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ARTICLE

The UK National Artificial Eye Questionnaire Study: predictors of artificial eye wearers' experience Part 2 – visual function and quality of life

Yinon Shapira[1] · Emma Worrell[2] · Andre S. Litwin[1] · Raman Malhotra[1]

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Abstract

Objectives To report associations with visual function and quality of life (QOL) in artificial eye wearers.

Methods Multicentre, observational, cross-sectional, nationwide study, within the National Health Service England. Items were adopted from the National Eye Institute Visual Function Questionnaire, and incorporated in the National Artificial Eye Questionnaire (NAEQ). The NAEQ was completed by 951 respondents. Multiple regressions assessed associations between the QOL scores and the experiences of artificial eye wearers, their routine management, changes over time, baseline and demographic parameters.

Results Parameters predictive of a better QOL composite score included longer artificial eye wear ($\beta = 0.18$, $p < 0.001$), better appearance ($\beta = 0.17$, $p < 0.001$), better comfort ($\beta = 0.14$, $p = 0.001$), tumour-related anophthalmia ($\beta = 0.13$, $p = 0.003$), male gender ($\beta = 0.13$, $p < 0.001$), shorter period of adjustment to monocular vision ($\beta = 0.12$, $p < 0.001$) and use of soap for cleaning ($\beta = 0.09$, $p = 0.046$). The composite score continued to improve beyond 10 years of prosthesis wear (≤2 years mean 72.80 ± 1.65 versus >10 years mean 79.45 ± 0.70; $p = 0.001$). Both better prosthesis appearance ($\beta = 0.14$, $p = 0.022$) and improved motility ($\beta = 0.13$, $p = 0.042$) predicted a better dependency score. Use of lubricating ointment predicted a worse dependency score ($\beta = 0.23$, $p = 0.003$). Neither the frequency of removal, nor the cleaning frequency of the artificial eye correlated with QOL scales.

Conclusions Multiple factors in the artificial eye experience were found to predict visual function and QOL aspects. This study underscores the need to generate a dedicated QOL questionnaire for use in anophthalmic patients.

Introduction

Evidence regarding the emotional, psychosocial and quality of life (QOL) implications of artificial eye wear emphasise the importance of providing emotional support or counselling in order to maximise long term QOL [1, 2]. Individuals with an artificial eye were shown to have lower health-related QOL scores [1, 3], with perceptions of their social relationships negatively affected, whilst being prone to suffer from anxiety and depression [1].

Nevertheless, little has been published regarding functional and/or vision-related QOL aspects in these patients [4]. Furthermore, in the published research into the impact of an AE on the psychosocial well-being and QOL of the wearer, the measurement tools varied by way of multiple types of questionnaires and scales utilised. The main reason may be the lack of an accepted or validated QOL questionnaire, dedicated to the unique aspects of the artificial eye and monocular state, which include significant emotional, social, aesthetic as well as visual function effects. For instance, a previous study employed the Short-Form 36-Item Health Survey (SF-36) among anophthalmic patients [1], which is considered a general health-related QOL instrument. Others have used the Derriford Appearance Scale short form (DAS24) as a measure of social anxiety and social avoidance in relation to appearance, and the

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✉ Yinon Shapira
yinonshapira@gmail.com

[1] Corneoplastic Unit, Queen Victoria Hospital NHS Foundation Trust, East Grinstead, West Sussex, UK

[2] Maxillofacial Prosthetics, Queen Victoria Hospital NHS Foundation Trust, East Grinstead, West Sussex, UK

Hospital Anxiety & Depression Scale (HADS) which is a measure for depression and anxiety in patients with physical health problems [5]. Saxby et al. [6] on the other hand, created a custom 9-item questionnaire in order to evaluate the emotional and psychosocial well-being of anophthalmic patients.

The UK National Artificial Eye Questionnaire (NAEQ) Study was devised to address the unmet need to establish an organised, wide-reaching and comprehensive database in order to substantialise information pertaining to patient education and expectation management [6]. The NAEQ provides data covering patient demographics, the aetiology of sight or eye loss, adjustment time to monocular vision, comfort, discharge, and satisfaction of appearance, routine management, and care experiences, as well as aspects related to visual function and QOL (as measured by items incorporated from the National Eye Institute Visual Function Questionnaire [7]).

Part 2 of the current study aims to assess how patients' demographics, aetiology of anophthalmia, length of (any) prosthesis wear, adjustment time to to daily life with monocular vision, discharge levels, polishing and routine care may associate with the visual function and QOL of artificial eye wearers. Personal testimonials related to mental health, visual function and QOL were also discussed.

Subjects and methods

The methodology has previously been discussed in Part 1 [8] in detail. It is briefly summarised herein.

Study design and recruitment

This national, observational, cross-sectional questionnaire study was granted approval by the National Research Ethics Service and was performed over 40 sites, nationwide within the National Health Service (NHS) England. The study received support from the National Institute for Health Research Clinical Research Network (NIHR CRN) Portfolio.

The National Artificial Eye Questionnaire (NAEQ) was available to patients 18 years of age or older attending NHS eye services or maxillofacial prosthetic services.

Recruitment for the study started in July 2017 and ended in April 2019, with final recruitment of 957 artificial eye respondents.

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 completed by the respondent. All testimonials (193), grouped by category, are presented in Supplement 2.

In order to assess visual function and QOL parameters which are related to the prosthetic eye condition, 15 items were adopted from the National Eye Institute Visual Function Questionnaire (NEI VFQ-25 [7], version 2000) and were incorporated in the NAEQ. In order not to render the NAEQ excessively laborious for respondents, the panel determined that the incorporation of these particular 15 items would be the minimum enabling measurement of QOL and visual function parameters that are relevant to AE wear. Some of the items' format was slightly changed from the original in order to suit the AE/monocular scenario. The developers of the NEI VFQ-25 acknowledge that researchers may need to change the format of items to suit their purposes (as stated in the NEI VFQ-25 manual).

Each of these items in the questionnaire was assigned to subscales in accordance with the NEI VFQ-25 manual: general health (1 item), general vision (1 item), near vision activities (2 items), distance vision activities (2 items), social functioning (2 items), mental health (2 items), role difficulties (3 items), dependency (one item assessing the respondent's degree of avoidance of leaving their home) and driving (one item indicating whether the respondent is currently driving or not).

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 (on a 0–100% scale). Multi-item scores were averaged to generate the specific subscales. The overall QOL composite score was calculated by averaging the subscales scores, excluding the general health item.

Data were analysed with StatSoft Statistica software, version 10 (StatSoft, OK, USA). 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 or binomial logistic model, as appropriate). The regression models are presented with their respective whole model R^2 and regressors' partial r (β coefficient), or with respective odds ratio (OR), as appropriate. A two-sided p value of <0.05 was considered statistically significant.

Results

The overall data of QOL scores in relation to baseline and prosthesis-related parameters of the total length of prosthesis time (i.e., length of time an individual has had any prosthesis), length of current prosthesis time, comfort level, discharge level, eye appearance, motility, adjustment time to daily life with monocular vision, rating of polishing effect, lubrication frequency, lubrication modality and cleaning method is presented in Tables 1 and 2. The univariate analyses are detailed in Supplements 3 and 4.

Demographic factors

Tumour-associated loss of the eye predicted better QOL composite, near vision activities, social functioning (Table 1) and general health (Table 2) scores compared to *other* aetiologies (i.e., eye disease not related to trauma, congenital reasons or tumours).

Older age (both >65 and 50–65 years categories) predicted lower general health and general vision scores compared to the youngest age group (18–30 years). The 30–50 years age category was not significantly different when compared to 18–30 years (Table 2). Age over 65 years predicted lower distance vision activities score compared to 18–30 years of age, whilst 50–65 years and 30–50 years age categories were not significantly different when compared to 18–30 years (Table 1). The age group 30–50 years had higher odds of active driving than the 18–30 years age group, whilst age over 65 years, as well as the 30–50 years age category, were not significantly different when compared to 18–30 years (Table 2).

Males had better scores in the composite, near vision activities, social functioning, mental health, role difficulties and dependency scales (Table 1). Also, males were more likely to be active drivers (Table 2).

Length of time of artificial eye wear

The longer the respondent had been wearing the artificial eye (i.e., since his first-ever fitted prosthesis), the better the composite score, as well as the subscale scores of near vision activities, distance vision activities, social functioning, mental health, role difficulties and dependency (Table 1). After categorising length of artificial eye wear to 0–2 years; 3–5 years; 6–10 years; and >10 years, post-hoc pairwise comparisons revealed that longer than 10 years of wear correlated with better scores on the composite as well as the specific subscales (see Supplement 5 for the detailed post-hoc pairwise analysis for the composite score; subscales' analyses data is not presented).

There was a correlation between a longer adjustment time to monocular vision and a worse score in the composite as well as near vision activities, distance vision activities, social functioning, mental health and role difficulties (Table 1).

Comfort and discharge

Better prosthesis-related comfort predicted better scores in the composite, near vision activities, distance vision activities, social functioning, mental health and role difficulties (Table 1). There were fewer active drivers among respondents that reported that they experienced discomfort "all of the time" specifically when driving compared to those who experience it less frequently (47.6% vs. 61.0–86.6% active drivers, respectively; $p < 0.0001$).

The average discharge score did not predict any of the QOL scores (Tables 1 and 2).

Prosthesis appearance

Better self-rated artificial eye appearance predicted better composite score, social functioning, mental health, role difficulties, dependency (Table 1) and general vision (Table 2). Interestingly, prosthesis motility predicted only a better dependency score (Table 1).

Lubrication and prosthesis care

The need for less lubrication predicted better scores in distance vision activities and social functioning subscales (Table 1). It also predicted slightly greater odds for active driving (OR 1.01, $p = 0.013$; Table 2). Ointment use was associated with a worse dependency score compared to drops or *other* lubrication modalities (Table 1).

There were no associations between the time that has elapsed since the last polishing of the prosthesis and any of the scales (Supplement 3). Respondents that rated a higher beneficial effect of prosthesis polishing were slightly more likely to be active drivers (OR 1.01, $p = 0.007$; Table 2).

Neither the frequency of removal nor the cleaning frequency of the artificial eye correlated with any of the QOL scales (Supplement 3). Interestingly, respondents that used soap to clean the prosthesis had better composite score compared to users of other cleaning methods (i.e., neither soap nor water; Table 1).

Testimonials relating to visual function, QOL and mental health

Free-text comments relating to QOL and visual function constituted almost one third (57/193 total comments, 29.5%) of all aspects covered in the artificial eye wear experience, making this the most frequent category respondents related to (Supplement 2). Of the testimonials

Table 1 Multiple regression analyses for the predictive values of baseline and prosthesis-related parameters regarding visual function and quality of life items[a], in 951 Artificial Eye Questionnaire respondents.

VFQ (subscale)		Composite score[b]		Near vision activities[c]		Distance vision activities[c]		Social functioning[c]		Mental health[c]		Role difficulties[c]		Dependency	
		Multiple R squared[d] = 0.18		Multiple R squared[d] = 0.12		Multiple R squared[d] = 0.17		Multiple R squared[d] = 0.11		Multiple R squared[d] = 0.22		Multiple R squared[d] = 0.12		Multiple R squared[d] = 0.12	
Parameter	Category	β coefficient	p value	β coefficient	p value	β coefficient	p value	β coefficient	p value	β coefficient	p value	β coefficient	p value	β coefficient	p value
Total time of having any prosthesis (years)		**0.18**	<0.0001	**0.14**	0.0003	**0.22**	<0.0001	**0.09**	0.011	**0.18**	0.001	**0.21**	<0.0001	**0.11**	0.027
Length of current prosthesis time (years)		0.00	0.91	0.01	0.68	0.05	0.18	NI		0.03	0.51	NI		NI	
Comfort level[e]		**0.14**	0.0001	**0.10**	0.007	**0.12**	0.001	**0.11**	0.003	**0.20**	0.0001	**0.11**	0.042	0.04	0.46
Discharge level[e]		0.03	0.39	0.07	0.060	0.01	0.71	−0.02	0.67	0.06	0.23	−0.01	0.84	0.01	0.79
Eye appearance		**0.17**	<0.0001	0.07	0.094	0.08	0.051	**0.16**	0.0001	**0.19**	0.001	**0.13**	0.042	**0.14**	0.022
Motility		0.04	0.33	0.03	0.54	0.03	0.52	0.00	0.94	0.03	0.61	0.05	0.41	**0.13**	0.042
Time taken to adjust to monocular vision (years)		**−0.12**	0.0003	**−0.07**	0.039	**−0.12**	0.0004	**−0.11**	0.003	**−0.11**	0.022	**−0.10**	0.045	−0.04	0.38
Degree of beneficial effect of polishing		NI		NI		NI		NI		NI		NI		0.01	0.86
Lubrication frequency		0.07	0.058	0.04	0.25	**0.11**	0.005	**0.09**	0.022	0.09	0.085	0.02	0.66	0.02	0.65
Background aetiology	Trauma	0.04	0.33	0.09	0.054	0.04	0.45	0.03	0.55	−0.07	0.28	−0.02	0.81	NI	
	Congenital	0.01	0.16	0.08	0.062	−0.01	0.73	0.01	0.81	0.03	0.64	−0.04	0.53		
	Cancer	**0.13**	0.003	**0.15**	0.0006	0.07	0.097	**0.11**	0.014	0.05	0.43	0.04	0.50		
	Other														
Age (years)	≥66	NI		NI		**−0.24**	0.002	NI		0.00	0.97	NI		0.02	0.83
	>50–65					−0.12	0.086			−0.10	0.34			−0.02	0.86
	>30–50					0.02	0.69			−0.03	0.76			0.02	0.84
	18–30														
Gender	Male	**0.13**	<0.0001	**0.14**	<0.0001	**0.15**	<0.0001	**0.10**	0.005	**0.16**	0.001	**0.13**	0.012	**0.12**	0.014
	Female														
Ethnicity	White	NI		NI		NI		NI		0.06	0.39	NI		NI	
	Black									0.09	0.11				
	Asian									0.02	0.72				
	Other														
Prosthesis cleaning method	Water	−0.03	0.45	−0.03	0.51	−0.05	0.27	−0.06	0.19	−0.03	0.64	−0.02	0.76	NI	
	Soap														
	Other	**−0.09**	0.046	−0.09	0.054	−0.04	0.33	−0.07	0.13	−0.02	0.68	−0.08	0.24		
Lubrication modality	Drops	NI		NI		NI		NI		0.07	0.34	0.07	0.36	**0.23**	0.003
	Ointment														
	Other									0.13	0.10	0.04	0.58	**0.18**	0.024

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

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

Categories in italics mark the reference category.

[a]Adopted from the National Eye Institute Visual Function Questionnaire (NEI-VFQ).

[b]Average score of the subscales (excluding General Health and Driving).

[c]Average score of items to generate subscales.

[d]Multiple regression (general linear model) R^2.

[e]Average score of all items rated in this parameter-related category.

Table 2 Multiple regression analyses for the predictive values of baseline and prosthesis-related parameters regarding general health, general vision, and likelihood of driving[a], in 951 Artificial Eye Questionnaire respondents.

VFQ item		General health		General vision		Driving	
		Multiple R squared[b] = 0.07		Multiple R squared[b] = 0.07			
Parameter	Category	β coefficient	p value	β coefficient	p value	Odds ratio (95% CI)[c]	p value
Total time of having any prosthesis (years)		NI		NI		1.01 (0.999–1.014)	0.070
Length of current prosthesis time (years)		NI		NI		1.01 (0.990–1.029)	0.33
Comfort level[d]		NI		NI		NI	
Discharge level[d]		NI		NI		NI	
Eye appearance		0.07	0.053	**0.17**	<0.0001	NI	
Motility		0.06	0.13	0.00	0.95	NI	
Time taken to adjust to monocular vision (years)		−0.05	0.13	NI		NI	
Degree of beneficial effect of polishing		NI		0.04	0.24	**1.01** (1.002–1.015)	0.007
Lubrication frequency		0.07	0.12	NI		**1.01** (1.001–1.011)	0.013
Background aetiology	Trauma	0.02	0.62	0.05	0.33	1.27 (0.825–1.956)	0.28
	Congenital	0.06	0.15	−0.07	0.12	0.62 (0.336–1.137)	0.12
	Cancer	**0.09**	0.046	0.04	0.39	1.41 (0.867–2.284)	0.17
	Other						
Age (years)	≥66	**−0.26**	0.0004	**−0.28**	0.0001	1.24 (0.625–2.470)	0.54
	>50–65	**−0.21**	0.004	**−0.22**	0.002	1.93 (0.967–3.864)	0.062
	>30–50	−0.07	0.23	−0.09	0.16	**2.30 (1.113–4.770)**	0.025
	18–30						
Gender	Male	NI		0.06	0.11	**2.42 (1.760–3.333)**	<0.0001
	Female						
Ethnicity	White	NI		−0.07	0.24	NI	
	Black			0.00	0.96		
	Asian			0.00	0.97		
	Other						
Prosthesis cleaning method	Water	NI		−0.04	0.39	0.80 (0.520–1.241)	0.32
	Soap						
	Other			−0.07	0.15	0.58 (0.338–1.011)	0.055
Lubrication modality	Drops	NI			NI		NI
	Ointment						
	Other						

NI not included in the multiple regression (univariate $p > 0.1$), *CI* confidence interval.

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

Categories in italics mark the reference category.

[a]Adopted from the National Eye Institute Visual Function Questionnaire (NEI-VFQ).

[b]Multiple regression (general linear model) R^2.

[c]Multiple logistic (binomial) regression.

[d]Average score of all items rated in this parameter-related category.

in this category, the highest proportion (19/57, 33.3%) were related to adjustment to monocular vision. This included comments regarding the length of time taken to adjust, the fact that "You do not fully adjust to vision in one eye ever", the ease of adjusting if the loss of an eye occurred in childhood, and adjustment to daily activities such as sports ("I still play sports and am a shooter for my netball team, it doesn't affect my shooting ability"). The next prevalent issue, accounting for 15/57 (26.3%) comments in this category, concerned depth perception. This included testimonials regarding having to give up playing sports, driving and engaging in certain occupations specifically due to lack of depth perception ("I had to give up being a nurse because of loss of depth perception…"). Additionally, comments were made conveying difficulty in pouring drinks or serving meals and walking down steps. Some patients pointed out that depth perception is the most concerning, or even the only difficulty in their artificial eye experience. Loss of peripheral vision on the "blind side" was next (9/57 comment, 15.8%), with comments mostly spanning bumping into objects (to the extent of being often injured) and negative reactions from bumping into other people (particularly in crowded places, such as supermarkets and railroad stations). Other general comments, such as "Difficult

to adapt to varifocal lenses with only one eye", and general vision comments ("Difficult to put eye in with Macular Degeneration in other eye – often it's upside down") accounted for 7/57 (12.3%) of total comments. Unspecific effects on occupation, for example, "Having an artificial eye does impede job opportunities even though I have fairly good vision in my left eye", made up 5/57 (8.8%) of remarks. Interestingly, one respondent mentioned, "I am a qualified helicopter pilot!" Finally, 2 comments were made regarding the desire to be able to see three-dimensional films or virtual reality.

Testimonials expressing psychological aspects and general judgements about living with an artificial eye were grouped into a "Mental health and General attitudes" category. These were the third-most prevalent comments (41/193, 21.2%), following the QOL and appearance-related testimonials. The majority of testimonials in this category (26/41, 63.4%) expressed gratitude for having the artificial eye. Some representative examples include "It has changed my life 100% for the better", "I live life without worrying about my eye" and "Be positive. You do adjust. You forget you only have one eye." On the other hand, only 7 comments (17.1%) expressed frustration and anger, for example, "I have never been able to accept my loss (tumour at 2 ½), it's a living hell, every day and night all I think about is not having my other eye". Six comments (14.6%) expressed a sense of self-consciousness ("Self-conscious and anxious sometimes due to my artificial eye"). Lastly, only 2 comments expressed a fear of going blind or losing the good eye.

Discussion

The chief visual function problems in acquired monocular vision are reduced visual field and compromised depth perception [4, 9]. These have implications on daily activities such as sports and driving, as well as occupational ramifications, consequently affecting the quality of life and emotional well-being. It was suggested that over time, patients develop compensational strategies and are able to resume previous work and daily activities [10], and their initial distress diminishes [3]. The three most prevalent comments made by the respondents in the current study which were related to visual function and QOL indeed concerned monocular vision adjustment issues, depth perception and blind-side difficulties, respectively. However, these comments often conveyed hardships rather than triumphs. Fortunately, our analysis showed that the longer someone has an artificial eye, the better the QOL scores, regardless of whether the self-reported length of time to adjust was longer. This could provide hope for both the despaired novice patient and the frustrated care provider. Pine et al. [3] also demonstrated that the anophthalmic patient's initial concerns decrease after 2 years of wear. The current study adds that further improvement occurs beyond 10 years.

An important finding in this analysis was the strong association between artificial eye wearers' comfort level and better QOL scores. Thus, the comfort of these patients should be a key goal, encompassing dry socket symptoms, inflammation, allergic response, unsmooth prosthesis surface, poor fit and excess discharge [3, 11]. The multiple regression results suggest that discharge, without discomfort, may not influence QOL scores. This strengthens the finding, discussed in Part 1 [8], that discharge may not be the most important aspect for the perceived prosthesis comfort. Some of these observations are in accordance with that of Song et al. [12] In their report, discharge was the most common symptom, reported by 60% of patients. However, did not correlate with patient satisfaction [12].

Respondents with better QOL scores require less socket lubrication. As discussed in Part 1 [8], the extent of lubrication was the most predictive factor for the perceived comfort with the prosthetic eye. Thus, the fact that patients who use less lubrication have higher QOL scores may be an indicator of a more comfortable artificial eye leading to better QOL. Tear production is diminished and meibomian gland dysfunction greater in an anophthalmic socket [13, 14], and symptomatic patients require lubrication [15, 16]. There is no evidence that one lubricating substance is better than another for an artificial eye [17]. We found the use of an ointment was associated with a worse dependency score compared to artificial tears and *other* lubrication modalities (including oil). As the dependency score relates to the respondents' inclination to avoid leaving their home, this may attest to the profound consequence of a need to use more substantial (high-viscosity) lubrication modality to improve prosthesis tolerance, independent of the frequency of use.

There is no current agreement on the precise care needs for prosthetic eyes in terms of removal and cleanliness [5, 11, 13, 17–19]. The results of the current study imply that the cleaning regime should be individualised, as we found no association between removal or cleaning frequency and QOL. The results also suggest that patients seeking *other* cleaning methods, that is neither soap nor water, have lower QOL scores. It would be difficult to conclude if this denotes a causal relationship, or merely represents a subset of respondents that seek solutions where simple cleaning measures have failed. Our results do not support recommendations to avoid household soap nor to prefer the use of specialised cleaning solutions [17].

Unlike cleaning and lubrication guidelines, there is general (however unproven) consensus that acrylic prostheses should receive professional polishing once every 12 months, and

more frequently if irritation or discharge is present [17, 19]. Contrary to this, our current analysis found both the subjective perception that polishing improves prosthesis tolerance and the length of time that has elapsed from the last polishing were not associated with QOL scores. This is in line with results of a previous questionnaire survey of prosthetic eye wearers, in which 62% reported no improvement in discharge following professional polishing, or that any improvement lasted <1 month [20]. Similarly, the objective effect of optical quality polish for an improved prosthesis finish was not sustained beyond 1 month [11]. The respondents in the current study indicated that their last polishing was performed on average 3 years prior to participation, and therefore significantly longer than any assumed sustainability of polishing effect. This bias may hamper the possibility to identify significant correlations with QOL. We could also speculate that it importantly demonstrates that the participants in this nationwide cohort may not be provided with timely polishing.

Satisfaction among artificial eye wearers was linked amongst various factors to the ability to disguise disfigurement [4, 17]. In this study, the self-rated better appearance of the artificial eye was predictive of better QOL scores. Interestingly, the multiple regression results suggest that poor motility, without poor overall appearance, may not influence most of the QOL items. The noted exception was that improved prosthesis motility predicted a better dependency score, implying less avoidance of being seen in public. As discussed in Part 1 [8], the motility is regarded as very strongly linked to the general appearance, probably due to the importance of harmonised eye movement in social interactions, in order to disguise disfigurement. Thus, it is perhaps not surprising that poor motility should particularly be linked to fear of being seen socially. Indeed, in the study of Song et al. [12] the only variables significantly correlated to patient satisfaction were economic status, other people's response and insertion of a motility peg. Taken together, the multidisciplinary reconstructive team should aim to provide a prosthesis offering the best possible cosmetic match [11, 21], without underestimating the importance of good motility [12].

These results differ from the study of Ahn et al. [1], in which the appearance of the prosthetic eyes was not significantly associated with the health-related QOL or the levels of depression and anxiety. However, Ahn et al. [1] acknowledge in their study that the SF-36 is a generic instrument that contains items to measure general aspects of the health-related QOL, and therefore may not be able to measure clinically important changes in anophthalmic patients. Arguably, the QOL items incorporated in this questionnaire should capture aspects that are more specifically relevant to the prosthetic eye wearer, both in terms of visual tasks and other QOL aspects.

Finally, in the current study older age and female gender were associated with worse QOL scores. There is conflicting evidence regarding the effect of age or gender. Ahn et al. [1] reported a similar association between older age as well as female gender and a lower health-related quality of life. A previous study looking at the psychosocial and appearance-related concerns of a sample of ophthalmic patients (some of which were artificial eye wearers) has shown similar gender influence [22]. Female participants were found to experience greater levels of general anxiety, reported higher levels of distress and dysfunction in relation to their appearance, placed more value on their appearance, compared their appearance more often with others and evaluated their appearance more negatively than males. On the other hand, in the same study older age was related to appearance being less important and lower levels of appearance-related distress and dysfunction [22].

Lastly, while the NAEQ was designed to be comprehensive in terms of encompassing a wide range of aspects relevant to artificial eye wear, not all could be covered in a single questionnaire. For example, the questionnaire did not consider the number of surgeries or socket revisions a patient had to undergo as having an effect on QOL. Other limitations of this study stemming from the (self-reported) questionnaire methodology were discussed in Part 1 [8] and are relevant to the current Part 2. There are further, and specific limitations stemming from the way this questionnaire assessed QOL in artificial eye patients. For lack of a better option, measurement of QOL in the artificial eye scenario was accomplished by adopting items from the NEI-VFQ. While it is safe to assume that monocular vision implications are captured by the VFQ items, with specific effects in the different subscales (distance vision activities, near vision activities, social function, role difficulties, mental health and dependency), there are other aspects to the artificial eye experience which probably contributed or overlapped. This possibly explains why appearance and comfort perceptions were found to be associated with the QOL scales, which should be puzzling if only considered in the context of visual function. Furthermore, only selected items were incorporated from the validated NEI-VFQ25 questionnaire, and necessary format changes were applied to fit the AE and monocular states. Therefore, the results cannot be considered to be mirroring the validated Visual Function Questionnaire, predominantly designed and validated in the realm of vision-related effects [7]. Nevertheless, within the limitations disclosed, we believe that the current questionnaire incorporating a subset of NEI-VFQ items provides a more relevant instrument to assess QOL among artificial eye wearers than using a general health-related QOL tool. This study should underscore the need to generate consensus for a dedicated and validated QOL questionnaire for use in anophthalmic patients.

Summary

What was known before

- Evidence regarding the emotional, psychosocial and quality of life (QOL) implications of artificial eye wear emphasise the importance of providing emotional support or counselling.
- Questionnaires utilised in previous surveys were variable by way of the lack of an accepted or validated quality of life questionnaire, dedicated to the unique aspects of the artificial eye and monocular state.
- Very little is published regarding functional and/or vision-related quality of life aspects in these patients.

What this study adds

- This National Artificial Eyes Questionnaire study encompasses a vast array of experiences.
- Part 2 reports predictors of visual function and quality of life aspects.
- Improving comfort, and particularly dry sockets seem to be a key goal to improve quality of life.
- The perceived appearance and prosthesis motility seem to be linked with quality of life aspects.

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Compliance with ethical standards

Conflict of interest The authors declare no competing interests.

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