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## Original Article

# Concerns of anophthalmic patients wearing artificial eyes

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#### **ABSTRACT**

**Background:** To identify the concerns of experienced artificial eye wearers and investigate whether these had changed since they lost their eye.

**Design:** A retrospective study of private practice patients.

**Participants:** Sixty-three experienced artificial eye wearers.

Methods: An anonymous questionnaire was posted to participants. Paired Wilcoxon tests were used to investigate changes to concern levels over time. Ordinal logistic regression was used to investigate associations of demographic variables with concern levels.

Main Outcome Measures: Changes in level of concern over time.

Results: At the time of initial eye loss, participants were mainly concerned about the health of their remaining eye, coping with monocularity and receiving good advice. Between initial eye loss and the present, reductions in concern occurred with judging distance, peripheral vision, appearance, receiving good advice, comfort, retention, colour and movement of the artificial eye, fullness of orbit, loss of balance and postoperative pain. Patients whose jobs involved the public were more concerned about appearance and reduced visual range than those in other occupations. Participants' chief present-day

concerns were health of the remaining eye and watering, crusting and discharge. All results above had a probability <0.05.

Conclusions: The study emphasized patients' concerns about the health of their remaining eye and their need for good advice at time of eye loss. Knowledge that their initial concerns about judging distance, reduced peripheral vision and appearance all decrease over time may help clinicians in counselling these patients. Watering, crusting and discharge was the chief present-day concern after health of the remaining eye.

**Key words:** anophthalmia, artificial eye, ocular prosthesis, quality of life.

#### INTRODUCTION

The loss of an eye is a major event that impacts on a person's self image. The resultant monocular vision requires adaptations to perception because of the loss of binocular cues to depth and the reduction in visual field on the affected side. The changes in routine associated with wearing and maintaining an artificial eye add to the factors that affect anophthalmic patients' quality of life.

The literature on artificial eyes is primarily focused on issues that confront surgical teams and patients immediately before and after the loss of their natural eye. There is extensive literature on surgical procedures and on the perceptual implications of monocular vision.<sup>1</sup> A programme to help

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people adapt to the changes brought about by the sudden imposition of monocular vision has been proposed<sup>2</sup> and suggestions for fitting artificial eyes<sup>3</sup> are easily found. But there are few published studies that describe how people adapt to artificial eye wear over time.

Of the few that can be found Rasmussen and Rasmussen<sup>4</sup> identified that the most frequent complications associated with artificial eye wear are: secretion, lagophthalmos, enophthalmos, prosthesis instability and exophthalmos. Song *et al.* surveyed satisfaction of anophthalmic patients,<sup>5</sup> and Nicodemo and Ferreira have used a questionnaire to gauge the psychosocial profile of the patient with anophthalmia.<sup>6</sup>

The long-term experience of artificial eye wearers has received little attention, and we could find no published research that examines the concerns of anophthalmic patients, nor how these concerns may change over time. This study aims to address this by identifying the concerns of experienced artificial eye wearers, determining whether their concerns changed over time and whether gender, age, occupation, time since losing the natural eye or time since having the existing artificial eye fitted might be associated with particular concerns.

#### **METHODS**

#### Recruitment

The database of the New Zealand Artificial Eye Service, a private health provider operating in the North Island of New Zealand, was queried to find people who were aged 18 years and over and who had at least 2-years experience wearing an artificial eye. Letters were sent to 278 individuals inviting them to return expressions of interest if they wished to participate in an extensive research project involving them in a number of interventions and assessments. Sixty-nine patients responded to this invitation and six subsequently dropped out. The remaining 63 were sent an anonymous questionnaire that they all completed and returned by post.

#### Questionnaire

The participants were aware that the questionnaire was the initial part of a wider investigation into factors affecting artificial eye wear. The method of recruitment, the questionnaire and the wider study had ethics approval from the University of Auckland Human Participants Ethics committee.

The questionnaire was divided into four sections: *Section 1* requested demographic information including: gender, age, occupation, date of eye loss and date of fitting the present ocular prosthesis.

Section 2 asked participants to use visual analogue scales (VAS) to mark their level of concern about each of eight general factors associated with artificial eye wear. A VAS was associated with each named factor. The named factors were drawn from the clinical experience of the authors. For each factor the participants were asked to recall how concerned they were when they initially lost their eye and also their present-day level of concern. The left end of each VAS scale was labelled 'not concerned', and the right end was labelled 'very concerned'. Following the eight named concerns participants were invited to add any additional general concerns they had about artificial eye wear. The format was such that a VAS was associated with each additional concern. The section ended with free text space and an invitation to provide additional comments.

Section 3 had the same structure as section 2 with a VAS associated with each concern. The questions pertained to patients' specific concerns about their artificial eye. Again there was a space after the named concerns for participants to add any additional artificial eye concerns and to indicate their level of concern with a VAS.

Section 4 asked participants whether they experienced watering, crusting and discharge (yes or no). It also invited them to consider which of the following three items concerned them the most: (i) watering, crusting and discharge; (ii) judging distance; or (iii) appearance. This section invited participants to make further comments about their experiences with these issues if they wished.

#### Statistical analysis

The participants' levels of concern for the items in sections 2 and 3 of the questionnaire were obtained from the VAS as a number from 0.0 to 10.0. Paired Wilcoxon tests were used to investigate whether levels of concern changed from the time of the initial loss of their natural eye to the present time.

Ordinal logistic regression was used to investigate the factors that could be associated with the present levels of concern. For all outcomes other than 'pain from the operation' and 'phantom sight sensation' the levels of concern were grouped into three ordinal categories. The three categories were VAS readings: (i) less than 3; (ii) from 3 to less than 7; and (iii) 7 or greater. The probability of low concern was modelled. Because of the limited distribution of VAS ratings for 'pain from the operation' and 'phantom sight sensation' these outcomes were treated as binary: either absent (VAS rating = 0) or present (VAS

rating > 0). Age, gender, occupation, time since eye was lost and the time since present artificial eye was fitted were included as the explanatory variables. Each concern was analysed separately. Occupations were classified into two groups for the purpose of this test. The public group (n = 33) involved patients whose occupations involved direct face-to-face communication with the public. The non-public group (n = 27) did not work directly with the public.

#### **RESULTS**

#### Study population

See Table 1. The participants in the study were not markedly different from the population from which they were drawn although with a higher ratio of women. The median age of participants was 65, and the youngest participant was 41.

#### Concerns of anophthalmic patients

## Concerns of anophthalmic patients when they first lost their eye

Participants' initial concerns are shown in column 2 of Table 2. Their main initial general concerns were: the health of the remaining eye (median level of concern 7.0), ability to judge distance (6.8), receiving good advice (6.6), reduced peripheral vision (6.2) and concerns about appearance (5.6). Their main initial specific concerns about artificial eyes were: retention (median level of concern 5.8), direction of gaze relative to the good eye (5.7), comfort (5.3), movement (5.3) and fullness of orbit relative to the good eye (5.3).

## Current concerns of anophthalmic patients after more than 2-year experience wearing an artificial eye

The chief present-day general concern for anophthalmic participants (column 3 of Table 2) was health of the remaining eye (median level of concern 6.7). This was followed by concerns about receiving good advice (3.3), reduced peripheral vision (3.1) and ability to judge distance (2.2). Change to appearance (1.7) was next, and loss of balance (1.3), phantom sight vision (0.8) and pain from the operation (0.5) were of little concern for the majority of participants.

The chief present-day specific concern about artificial eyes was watering, crusting and discharge (4.8) followed by concerns about direction of gaze (4.7), size relative to the good eye (4.3), fullness of the orbit and eyelid contour (4.3). Comfort (3.0), movement (2.6) and concerns about colour (2.0) were less concerning, and most participants were not troubled by artificial eye retention (1.7).

#### Change in levels of concern over time

Changes in level of concern over time are shown in columns 4 and 5 of Table 2. For all variables, where there was evidence of a real change the levels of concern decreased. The health of the remaining eye was the top concern initially and again at the present time. A change over time was not demonstrated for concern over the health of the remaining eye, phantom sight vision, direction of gaze relative to the good eye, size relative to the good eye, eye lid contour relative to good eye and watering, crusting and discharge.

**Table 1.** Key features of the group of patients invited to participate (anophthalmic patients >18 years with at least 2-years experience wearing an artificial eye) compared with the group of participants (the sample)

Characteristic	Patients invited to participate $(n = 278)$	Study participants ( $n = 63$ )
Gender		
Male	62%	56%
Female	38%	44%
Median age		
Male	61 years (range 9–89)	66 years (range 41-83)
Female	59 years (range 19–95)	64 years (range 41-83)
Median age at eye loss		
Male	22 years (range 1–82)	26 years (range 1–76)
Female	56 years (range 1–91)	30 years (range 1–71)
Anophthalmic side		
Left	45%	51%
Right	55%	47%
Both	1%	1%
Reason for eye loss		
Accident	61%	51%
Congenital	9%	8%
Medical	30%	41%
Median time since prosthesis fitted	1.92 years	1.67 years

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<b>Table 2.</b> Concerns of anophthalmic patients at time of eye loss and after more than 2-year experience wearing
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1	2	3	4	5	6
Concerns of	Initial median	Current median	Median change in level	10% and 90%	Paired Wilcoxon
anophthalmic patients	level of concern	level of concern	of concern over time	percentile	test <i>P</i> -value
General concerns					
Health of remaining eye	7.0	6.7	-0.2	-4.7, 4.7	0.26
Ability to judge distance	6.8	2.2	-2.3	-7.2, 0.3	0.0001
Receiving good advice	6.6	3.3	-1.2	-6.3, 1.0	0.0003
Reduced side vision	6.2	3.1	-2.5	-6.8, 0.2	0.0001
Change to appearance	5.6	1.7	-2.2	<b>−</b> 7.5, 1.0	0.0001
Loss of balance	2.6	1.3	-0.2	-6.0, 0.5	0.0005
Pain from operation	2.1	0.5	-0.8	-7.2, 0.0	0.0001
Phantom sight vision	1.2	0.8	-0.2	-4.3, 2.5	0.38
Artificial eye concerns					
Retention of artificial eye	5.8	1.7	-1.8	<b>−</b> 7.8, 0.5	0.0001
Direction of gaze relative to good eye	5.7	4.7	0.0	-4.7, 2.5	0.37
Comfort of artificial eye	5.3	3.0	-1.8	-6.2, 3.3	0.0002
Movement of artificial eye	5.3	2.6	-1.4	-5.2, 3.7	0.0003
Fullness of orbit relative to good eye	5.3	4.3	-0.2	-4.2, 0.8	0.04
Size relative to good eye	4.8	4.3	0.0	-4.2, 3.0	0.15
Colour relative to good eye	4.3	2.0	-0.2	-4.7, 0.3	0.007
Watering, crusting and discharge	4.3	4.8	0.0	-4.7, 4.5	0.82
Eye lid contour relative to good eye	3.8	4.3	0.0	-2.8, 3.8	0.34

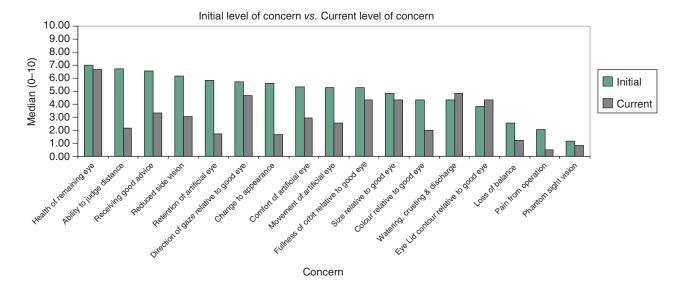


Figure 1. A comparison of levels of concern over a time period of greater than 2 years.

Figure 1 illustrates the dynamics of the change in levels of concern over time. The initial concerns are arranged with the highest levels on the left and the lowest on the right.

#### Other concerns identified by participants

Individual participants identified a number of concerns in addition to the concerns named in the questionnaire by the researchers. These are shown in Table 3.

#### Watering, crusting and discharge

Almost all of the participants (93%) reported experiencing watering crusting and discharge with 60% of these indicating that this occurred on a daily basis.

#### **Participants' comments**

The large percentage of participants (66%) who volunteered comments indicated that the questionnaire tapped into significant areas of concern. Forty-six per

**Table 3.** Concerns of anophthalmic patients additional to those already itemized in the questionnaire

General concerns	Artificial eye concerns
Future appearance because of aging	Removing and inserting
Lower lid laxity	Loss or damage
People staring at the prosthesis	Fixed pupil size
Communicating with people on the blind side	Rotating prosthesis when rubbing
Ability to earn a living	
Ability to drive	
Adjusting to use the opposite eye for sighting	

Table 4. Associations of demographic variables with levels of current concern

Current concern	Explanatory variable	Odds ratio <sup>†</sup> and Wald 95% confidence limits	<i>P</i> -value
Reduced side vision	Gender (female vs. male)	2.4 (0.72–7.8)	0.16
	Age	1.0 (0.89–1.1)	0.94
	Occupation (non-public vs. public)	4.0 (1.2–13.7)	0.03
	Time since natural eye lost	0.99 (0.96–1.0)	0.27
	Time since artificial eye fitted	1.0 (0.91–1.1)	0.73
Retention of artificial eye	Gender (female vs. male)	1.2 (0.34–4.1)	0.80
	Age	0.91 (0.81–1.0)	0.13
	Occupation (non-public vs. public)	0.90 (0.25–3.2)	0.87
	Time since natural eye lost	0.98 (0.95–1.0)	0.22
	Time since artificial eye fitted	1.2 (1.0–1.3)	0.01
Watering, crusting and discharge	Gender (female vs. male)	0.60 (0.20–1.8)	0.36
	Age	0.91 (0.81–1.0)	0.10
	Occupation (non-public vs. public))	1.3 (0.43–4.0)	0.64
	Time since natural eye lost	0.98 (0.96–1.0)	0.23
	Time since artificial eye fitted	1.1 (1.0–1.3)	0.03
Change to appearance	Gender (female vs. male)	0.51 (0.16–1.6)	0.26
	Age	0.97 (0.86–1.1)	0.58
	Occupation (non-public vs. public)	3.3 (0.98–11.3)	0.05
	Time since natural eye lost	0.99 (0.97–1.0)	0.70
	Time since artificial eye fitted	1.1 (0.94–1.2)	0.35

<sup>†</sup>Modelling the probability of no concern, that is, an odds ratio of >1 means higher odds of no concern.

cent of the comments were about watering crusting and discharge, 23% about appearance, 17% about perceptual issues and 14% about other concerns.

### Associations of demographic variables with levels of concern

With noted exceptions, there was no evidence of associations between current levels of concern and age, gender, occupation, time since the eye was lost or time since the present artificial eye was fitted (Table 4). The exceptions were in patients whose occupations involved face-to-face contact with the public where the odds of being concerned about their appearance and about reduced side vision were three and four times, respectively, the odds of those whose jobs did not involve the public. Also patients who had worn their present artificial eye for longer were less concerned about watering crusting and discharge and retention than those with newer artificial eyes.

#### **DISCUSSION**

The database of the New Zealand Artificial Eye Service from which the study population was drawn may not be representative of the over 18 years of age anophthalmic population in New Zealand. Notably, participants were an older group resident in the upper North Island. Also, the recency of manufacture of the current artificial eye (median age 1.92 years) suggests that patients were well maintained, which is not necessarily the case for people in the wider community. Further limitations of the study include the likelihood that it attracted older participants who arguably had more time and interest to participate. The age group expected to be in active employment were quite well represented with 42% of participants under the normal retirement age of 65 years. The low response rate from those initially invited to participate in investigations of artificial eye wear and from which the sample population was drawn may have resulted in individuals with particularly high

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or low levels of satisfaction with their prosthesis being more likely to participate. The study did not link the cause of eye loss to particular concerns, and it may be that prosthesis wearers experience different concerns or concern levels depending on whether eye loss was congenital or because of accident or medical reasons. A survey of patients from a range of public as well as other private sources could address this question.

The questionnaire has allowed experienced wearers of artificial eyes to provide insights into concerns that are relevant for new anophthalmic patients and the clinicians who care for them. These insights encourage health-care teams to be alert to answer carefully patients' questions about their remaining eye and to be knowledgeable about the perceptual impact of monocular vision. The evidence that the anophthalmic patient's initial concerns decrease over time may be of assistance to clinicians when counselling patients. New patients may also take heart from the study of Song et al., 5 which reported an overall rate of satisfaction with initial artificial eyes of 71.8%. Participants' voluntary comments highlighted the main concern factors and enriched the data. The health of the remaining eye was their chief concern throughout, and this reinforces the wisdom of advising patients to undergo regular clinical examinations of their remaining eye at periods appropriate for each particular patient. Protection of that eye with impact resistant non-prescription or prescription safety lenses<sup>7</sup> together with an appropriately safe frame design may also provide peace of mind for patients.

The chief current concern for participants after health of the remaining eye was watering, crusting and discharge. This result was accentuated by the high proportion of participants experiencing discharge (93%) and the large number of comments volunteered about the discharge problem. From this evidence the authors conclude that further research into the nature and management of watering, crusting and discharge is warranted.

The analysis of associations of demographic variables with current levels of concern showed that anophthalmic patients in public occupations were more concerned about their appearance than patients in non-public occupations. This result might be expected. The analysis also showed that they had greater concerns about reduced peripheral vision. This merits further investigation as it seems that anophthalmic patients may feel more uncomfortable with their limited visual range in public settings than in other situations. Length of time since the present artificial eye was fitted was associated with decreased levels of concern about retention and watering, crusting and discharge. The reason these concerns changed in this manner may have been

because problems with the earlier artificial eye were resolved with the replacement prosthesis.

The least initial level of concern was phantom sight vision. This is a common phenomenon for patients when they first lose their natural eye,<sup>8</sup> but it appears to worry them less than the other concerns they are dealing with at the time.

Aside from watering, crusting and discharge, the artificial eye concerns that changed the least over time were concerns about direction of gaze, size and eye lid contour. These concerns largely relate to surgical and technical details of the anophthalmic socket and were more concerning for present-day artificial eye wearers than concerns about the characteristics of their prostheses.

The study highlights the importance to anophthalmic patients of the health of their remaining eye and their need for good advice at the time of eye loss. Anophthalmic patients' initial concerns about ability to judge distance, reduced peripheral vision and change to appearance all decrease over time. Patients whose occupations involved face-to-face contact with the public were more concerned about their appearance and reduced visual range than those whose jobs did not involve the public. Watering, crusting and discharge warrants further study as this problem is a pervasive and inconvenient condition associated with artificial eye wear – it was the main current concern for anophthalmic patients after health of the remaining eye.

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