

## Research Article

# Time Heals: An Investigation into How Anophthalmic Patients Feel about Eye Loss and Wearing a Prosthetic Eye

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## Introduction

The loss or disfigurement of an eye and the subsequent use of an ocular prosthesis is due to a wide variety of accident, medical and congenital causes. A prosthetic eye is used to replace a missing natural eye, while sclera shell prosthesis fits over a disfigured non-functioning eye [1].

Every part of the human body holds significance and function; however, the face is particularly unique. It is principally how individuals are recognized and what is recalled when the person is absent. The face communicates perceptions, intensity of emotion, awareness, and ideas. Eyes in particular convey understanding and insight, and have an important role in non-verbal communication and self-expression. A number of studies have explored appearance related feelings of individuals following eye loss [2-4].

As well as self-image issues, anophthalmic patients must also contend with acquired monocular vision and the inconvenience of mucoid discharge associated with wearing a prosthetic eye. This study explores the emotional effects of living with a prosthetic eye

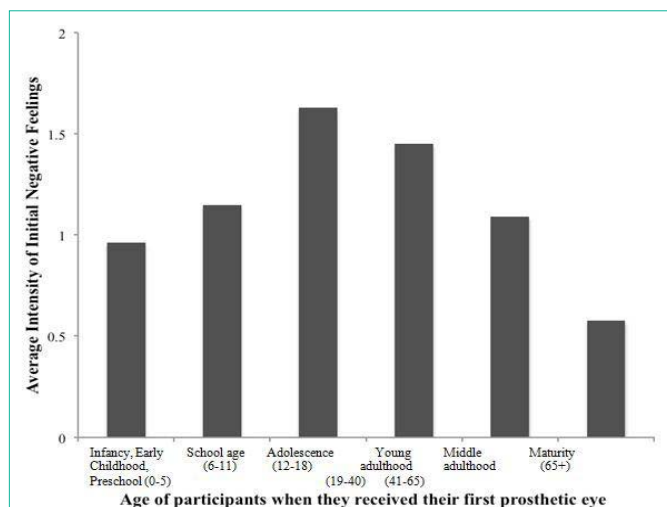
with particular attention to appearance, mucoid discharge and altered visual perception. It covers two periods of time - the first three months after receiving their first prosthetic eye and the present time, at least two years later.

The feelings and experiences of prosthetic eye wearers is an important area of study which has received little research attention in the past. The findings will provide clinicians with a greater understanding of the psychological impact of eye loss and enable them to reduce anophthalmic patients' potential distress.

## Materials and Methods

### Recruitment

Participants were recruited from the database of the New Zealand Prosthetic Eye Service, which is a private practice with clinics spread over the North Island of New Zealand. Participants had worn an ocular prosthesis for at least 2 years and were aged 16 years or above. The method of recruitment and the questionnaire was granted ethics approval by the Massey University Human Ethics Committee. Participants were provided with an information sheet and informed



**Figure 1:** Participants' average ratings of the intensity of initial negative feelings and the age they received their first prosthetic eye. Age groups are referenced from Erikson's (1963) [19] developmental stages.

that completion of the questionnaire implied consent. Of the 540 potential participants contacted about the research, 217 completed the questionnaire (40% response rate).

**Questionnaire**

The questionnaire included 29 questions and 5 psychological scales across 4 main categories (demographics, concerns, feelings and problems, psychological scales). This paper covers the feelings section of the questionnaire. That is, respondents were asked to rate the extent to which they felt positive and negative feelings on a 4-point Likert scale (0 = none and 3 = a great deal) with respect to the first three months of receiving their first prosthetic eye (initial) and at the time of completing the questionnaire (current). Negative feelings included: shame, insecurity, inferiority, sadness, blame, anger, shyness, fear, and preoccupation with hiding the disfigurement

[5]. Positive feelings included: happiness, relief, and acceptance. This paper also reports participants' concerns regarding appearance, mucoid discharge, and visual perception, as well as demographic information gathered (age, gender, age when first prosthesis received, etiology of eye loss).

**Data analysis**

The Statistical Package for the Social Sciences for Mac (version 23) was used to analyse the quantitative data. Paired samples t-tests were used to investigate differences between participants' initial and current intensity of feelings. Independent t-tests were used to analyse differences between: the ages at which participants received their first prosthetic eye and etiology of eye loss; the strength of both initial and current feelings and etiology of eye loss; the strength of negative feelings and levels of concern (discharge, appearance, visual perception); and strength of feelings according to gender.

Pearson correlations were conducted to investigate relationships between the age of participants when they received their first prosthetic eye and initial and current intensity of feelings, while multiple regressions were used to explore relationships between both initial and current concerns and strength of feelings.

**Results**

**Participants**

The majority of participants were male (67%) and ethnicities were: New Zealand European (76%), Maori (13%), other (7%), Asian (3%), and Pacific Islander (1%). The mean age of participant's was 58 years and their mean prosthetic eye wearing time was 27 years.

The gender ratio on 67% of men in the study population roughly aligns with the 59% of men in a larger survey of prosthetic eye wearers in New Zealand [6]. The representation of New Zealand Europeans (76%) and Pacific Islanders (1%) aligns with that in the general New Zealand population (75% and 0.08% respectively) [7]. However, there is an under representation of Maori (13%) and Asian (3%) ethnicities

**Table 1:** Percentages of participants' initial and current feelings according to intensity, and differences between initial and current mean intensity of feelings as scored on a 4-point Likert scale (0 = none and 3 = a great deal).

	Initial intensity of feeling (%)			Current intensity of feeling (%)			Mean initial intensity	Mean current intensity	Mean difference	Sig.
	None	Moderate	Strong	None	Moderate	Strong				
<b>Negative feelings</b>										
Shame	59.6	26.9	13.5	75.5	22.7	1.8	0.84	0.36	0.48	.000*
Insecurity	31.9	44.8	23.3	45.5	48.5	6	1.39	0.81	0.58	.000*
Inferiority	45	35	20	67.5	28.4	4.2	1.15	0.54	0.61	.000*
Sadness	31.3	42.9	25.8	57.9	36.6	5.5	1.41	0.66	0.76	.000*
Blame	64.9	24.6	10.4	81.5	14.2	4.3	0.67	0.32	0.35	.000*
Anger	50.3	31.8	17.8	68.5	25.5	6.1	1.02	0.47	0.55	.000*
Shyness	29.2	44.1	26.7	48.8	42.8	8.4	1.46	0.79	0.68	.000*
Fear	46.5	40	13.5	68.9	29.8	1.2	0.96	0.41	0.55	.000*
Preoccupation with hiding eye	43.7	36.1	20.3	52.4	39.2	8.4	1.16	0.73	0.43	.000*
<b>Positive feelings</b>										
Happiness	45.8	35.9	18.3	31.2	37.5	31.2	1.12	1.56	-0.44	.000*
Relief	37.4	42.6	20	40.3	34.4	25.3	1.26	1.35	-0.09	0.31
Acceptance	22.4	55.3	22.4	13.6	40.3	46.2	1.54	2.09	-0.54	.000*

\*The mean difference is significant at the 0.05 level.

**Table 2:** Differences in average strength of initial feelings according to etiology of eye loss and controlling for age when participants received their first prosthetic eye.

	Loss of eye due to accident	Loss of eye due to medical event	Mean difference	Sig.
<b>Initial negative feelings</b>				
Shame	1.02	0.54	.48	.021*
Insecurity	1.51	1.27	.24	.256
Inferiority	1.32	0.81	.51	.016*
Sadness	1.69	1.12	.57	.007*
Blame	0.92	0.33	.59	.003*
Anger	1.23	0.70	.53	.015*
Shyness	1.59	1.28	.31	.142
Fear	1.09	0.71	.38	.059
Preoccupation with hiding eye	1.23	1.04	.19	.390
<b>Initial positive feelings</b>				
Happiness	1.06	0.98	.08	.706
Relief	1.20	1.20	.00	.994
Acceptance	1.60	1.40	.20	.297

\*The mean difference is significant at the 0.05 level.

compared to the general population (16% and 12% respectively) [7], possibly because it was an English language questionnaire.

## Feelings

Table 1 illustrates the intensity of participants' positive and negative feelings with respect to the first three months of receiving a prosthetic eye (initial) and at the time of completing the questionnaire (current). The intensity of negative feelings significantly decreased over time, while feelings of happiness and acceptance significantly increased.

## Feelings and impacting variables

**Etiology of eye loss:** Eye loss etiologies were medical (63.2%), accident (31.1%), and congenital (5.7%). Those who lost their eye due to accident were significantly younger when they first received their prosthesis ( $M = 28$  years,  $SD = 18.89$ ) compared to those who lost their eye due to a medical condition ( $M = 41$  years,  $SD = 24.04$ ,  $p < 0.001$ ). Further, eye loss or damage through accident resulted in greater initial feelings of shame, inferiority, sadness, blame, and anger compared to medical etiologies (Table 2).

At the current time and controlling for current age, participants who lost their eye due to an accident continued to experience significantly stronger feelings of anger ( $M = 0.63$ ,  $SD = 0.96$ ) compared to those who lost their eye following a medical event ( $M = 0.30$ ,  $SD = 0.71$ ,  $p = 0.032$ ). There were no other significant differences between accident and medical etiologies and strength of feelings ( $p > 0.05$ ).

**Concerns:** Within the first three months of receiving a prosthetic eye, participants with higher discharge concerns reported stronger feelings of insecurity ( $r = 0.51$ ,  $p = 0.014$ ), preoccupation with hiding their eye ( $r = 0.53$ ,  $p = 0.047$ ), and weaker feelings of acceptance ( $r = -0.23$ ,  $p = 0.029$ ). Participants with higher appearance concerns reported stronger feelings of insecurity ( $r = 0.67$ ,  $p = 0.002$ ) and shyness ( $r = 0.67$ ,  $p = 0.001$ ) and those with higher visual perception concerns experienced stronger feelings of insecurity ( $r = 0.52$ ,  $p = 0.038$ ) and anger ( $r = 0.52$ ,  $p = 0.032$ ). At the current time, participants

with higher discharge concerns were more fearful ( $r = 0.14$ ,  $p = 0.040$ ) and preoccupied with hiding their eye ( $r = 0.51$ ,  $p < 0.001$ ). Those with higher visual perception concerns had stronger feelings of sadness ( $r = 0.39$ ,  $p = 0.049$ ), and those with higher appearance concerns were more preoccupied with hiding their eye ( $r = 0.70$ ,  $p < 0.001$ ). There were no other significant relationships between discharge, visual perception, and appearance concerns and strength of initial and current feelings.

**Age when participants received their first prosthetic eye:** On average, the participants of this study were 31 years old when they received their first prosthetic eye. Younger participants experienced stronger initial negative feelings ( $r = -0.13$ ,  $p < 0.001$ ) and continued to experience stronger negative feelings after at least two years compared to older participants ( $r = -0.07$ ,  $p = 0.017$ ). However, when controlling for participants older than 65 years, the relationship between age when participants received their first prosthetic eye and current negative feelings was no longer significant ( $p > 0.05$ ).

The relationship between the age when participants received their first prosthetic eye and their initial negative feelings may be linked to their developmental stage as illustrated in (Figure 1).

**Gender:** There were no significant differences in the intensity of feelings according to gender ( $p > 0.05$ ).

## Discussion

The finding that during the first three months of receiving their first prosthesis, participants experienced moderate to strong negative feelings (Table 1) is similar to Goiato et al.'s (2013) results [5]. These negative feelings occurred when anophthalmic patients were still processing the event, going through the early stages of grief [8], and coming to terms with their changed appearance and the functional impacts of eye loss. It is a very difficult and confusing time for patients and reassurance and good advice is critical at this time. In contrast to negative feelings, some participants reported moderate to strong feelings of happiness, relief and acceptance, which was probably a

positive response to the fitting of their prosthetic eye and a return to some sense of normality in their lives. Wang, Zhang, Chen, and Li's longitudinal study in 2012 [9] found that a significant decrease occurred in anxiety and depression symptoms, appearance-related social anxiety and social avoidance following the fitting of a prosthetic eye after enucleation.

Over time, participants' negative feelings decreased (also found by Goiato et al., [5]), while positive feelings increased. This reflected adjustment through the course of time, getting older [10], and the development of strategies to respond to others' comments/questions, to adjust to monocular vision, and to manage mucoid discharge, all of which were difficulties that negatively impacted mood early on.

There were continuing psychological impacts on some prosthetic eye wearers after at least two years of prosthetic eye wear, even though the intensity of these impacts lessened over time. Lingering negative feelings (mainly shyness and pre-occupation with hiding the eye) may be due to poor behavior from others, which can be internalized and become a part of an individual's self-image [11], leading to a more enduring sense of insecurity and shyness. Negative social, occupational, or recreational experiences can also create negative views of one's self leading to negative feelings which may be made worse by unhelpful coping strategies such as avoidance, which maintains negative beliefs as disconfirming information is never gained [12]. On the other hand, this study found that feelings of happiness and acceptance significantly increased after at least two years of prosthetic eye wear, which is an encouraging result that patients who have recently lost an eye should be made aware of.

The finding that eye loss due to an accident produced greater initial negative feelings compared to eye loss from a medical event, may reflect on the circumstances surrounding these different etiologies. Eye loss or damage following an accident is likely to be more sudden and unexpected and may not be in isolation of other injuries. These may also have to be coped with along with post-traumatic stress disorder, legal, financial and social issues not usually associated with medical events. Dealing with these issues may kindle anger, which could explain why feelings of anger were maintained for victims of accidents compared to medical events, while other feelings balanced out over time.

It is understandable that participants with greater initial and current concerns about mucoid discharge, visual perception and appearance would have negative feelings associated with each concern. Pine, Sloan, Stewart, and Jacobs [13] reported that 93% of anophthalmic patients experienced watering, crusting and discharge and that their second highest concern after health of the remaining eye was mucoid discharge. Participants with discharge concerns in this study initially reported stronger feelings of insecurity, preoccupation with hiding their eye and weaker feelings of acceptance, and while the intensity of these feelings decreased over time they were still more fearful and preoccupied with hiding their disfigurement than those without discharge concerns. It is important therefore that patients follow the protocol for managing discharge described by Pine, Sloan, and Jacobs [14], as discharge from the socket likely attracts unwanted attention and interferes with the disguisability of the ocular prosthesis. The anger initially experienced by participants with concerns about visual perception was possibly due to frustration as they misjudged

distance when performing everyday tasks and bumping into people and objects on their blind side.

Satisfaction with one's prosthetic eye is greater for those who feel their prosthesis is imperceptible to others [15], and many participants with appearance concerns in this study were particularly worried about the prosthesis moving in concert with their natural eye, the prosthesis rotating in the socket, and upper eyelid ptosis-all of which are factors linked to disguisability.

Participants' age when they first received their prosthesis impacted on the intensity of their negative feelings initially but after at least two years, these feelings had decreased and were not more or less intense than for anophthalmic patients who received their first prostheses at other ages. The lower intensity of negative feelings for children in infancy, early childhood and preschool stages (0-5 years) suggests that individuals with facial deformity from a young age have the opportunity to incorporate the irregularity into their body image, to develop effective coping strategies and to habituate to others' responses [16]. Individuals with congenital facial disfigurement also have less adjustment and psychological problems than those with acquired facial disfigurements [17]. The increase in intensity of negative feelings for school aged children (6-11 years) may be because at this developmental stage, children begin to compare themselves more to others, to define themselves by their appearance (as well as possessions and activities), and to recognize if they are different from others [18].

The developmental stage of adolescents largely focuses on identity and acceptance by peer groups [19], so it is not surprising that the strongest intensity of negative feelings were found to be during this stage. Adolescents are at a vulnerable stage where negative treatment by others (e.g., bullying, teasing) can have detrimental, long-standing impacts on their self-esteem and sense of worth [20]. Losing an eye at this age can predispose adolescents to such treatment and negatively impact on their sense of acceptance or belonging, leading to more salient negative feelings and reduced self-esteem. The heightened intensity of negative feelings for patients who lose their eye during adolescence highlights the particular importance of providing psychological support for adolescents who lose their eye. This support might include the provision of strategies to address others' comments, how to talk about it with others, building up self-esteem in important areas and training in compensatory strategies. Such support for adolescents may also reduce the level of social difficulties found to be greater in younger anophthalmic patients.

As adolescents move on to young adulthood (19-40 years) they are faced with the developmental task of establishing intimate and loving relationships with others [19]. Losing an eye during this period generated the second highest level of intensity of negative feelings with anophthalmic patients reporting feelings of insecurity, shyness, and inferiority as they struggle to form close relationships. The next developmental stage is middle adulthood (40-65 years) when people are mainly concerned with giving to the next generation and being committed to family and community [19]. Eye loss during this period generated less intense negative feelings than during young adulthood; however, concerns about acquired monocular vision and appearance impacting on employment may be one of the reasons for the presence of negative feelings during this stage.



Moving into maturity (65+ years), the developmental focus shifts to a person's sense of fulfillment about and satisfaction with their life [19]. Priorities shift away from cosmetic or outward appearance to physical functioning [21,22], meaning the negative feelings triggered by appearance concerns may become less salient and result in less negative emotional intensity accompanying eye loss during this period.

## Conclusion

Previous psychological research has focused almost exclusively on appearance-related issues but the results of this study demonstrate that discharge and acquired monocular vision, as well as appearance issues, can negatively affect the psychological wellbeing of anophthalmic patients. This study has also found that accident victims who lose an eye have stronger initial negative feelings than those who lose an eye because of medical conditions and that there appears to be a link between the strength of initial negative feelings and the developmental stage during which eye loss occurs with adolescents being most at risk. The authors recommend that psychological intervention and support be provided in the early stages following eye loss, especially for accident victims and adolescents, and that concerns regarding appearance, mucoid discharge, and acquired monocular vision be addressed. All patients can take heart from the finding that initial strong negative feelings decrease over time while positive feelings increase.

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