EVALUATION OF THE PSYCHOLOGICAL EFFECT AND VISION RELATED QUALITY OF LIFE IN ENUCLEATED/EVISCERATED PATIENTS WITH PROSTHETIC EYES

by

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DISCLAIMER

I hereby certify that the work in this is my own except for the quotations and summaries which have been duly acknowledged.

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ABSTRAK

Pengenalan:

Pesakit yang anoftalmia selepas pembedahan *evisceration* atau *enucleation* diwawancara tentang kehilangan mata dan juga proses patologi yang menyebabkan pembedahan dilakukan. Mata prostetik telah membantu pesakit untuk mendapat kesan kosmetik yang lebih baik selepas pembedahan. Pesakit anophthalmia mungkin mempunyai kesan psikologi yang tidak dikenal pasti oleh doktor yang merawat mereka. Oleh itu, mengenal pasti kesan psikologi tersebut adalah penting untuk membantu pesakit agar mereka boleh dirujuk kepada mereka yang berkenaan.

Objektif:

Tujuan utama kajian ini dilakukan adalah untuk menilai tahap kebimbangan, tekanan perasaan dan kualiti hidup pesakit dengan mata prostetik selepas pembedahan *evisceration* atau *enucleation* dan untuk menentukan peramal yang berpotensi berkaitan dengan masalah tersebut.

Kaedah:

Satu kajian keratan lintang telah dijalankan diantara Mac 2017 dan Mac 2018 melibatkan pesakit-pesakit yang menggunakan mata prostetik selepas pembedahan *evisceration* atau *enucleation* yang datang ke klinik mata dia dua hospital rujukan di Malaysia, Hospital Selayang dan Hospital Universiti Sains Malaysia. Pesakit-pesakit ini telah diberikan dua set soal selidik yang telah disahkan: *The National Eye Institute Visual Functions Questionnaire* – (NEI-VFQ) dan *Hospital Anxiety and Depression* (HADS). Selepas soal selidik

dilengkapkan, skor dijumlahkan dan dikira. Analisis statistik dilakukan menggunakan *Statistic Package for the Social Science* (SPSS *Inc* Versi 22).

Keputusan:

Seramai 54 orang pesakit telah mengambil bahagian dalam kajian ini. Pelbagai demografi dan pemboleh ubah klinikal yang telah diuji ataranya umur, jantina, bangsa, status perkahwinan, tahap pendidikan tertinggi, pendapatan bulanan, sebab pembedahan dan tempoh pemakaian mata prostetik. Purata komposit kualiti kehidupan berkaitan dengan visual berjumlah 75.97. Skor minimum adalah 18.75 dan skor maksimum adalah 100.

Purata skor bagi HADS (D) tekanan perasaan, adalah 1.94 dengan julat skor antara 0 sehingga 8. Seramai 53 pesakit telah memberikan skor normal dan seorang memberikan skor melebihi 8. Purata skor HADS (A) kebimbangan, adalah 3.61 dengan julat skor antara 0 sehingga 10. Seramai 48 pesakit memberikan skor normal dan 6 pesakit memberikan skor melebihi 8, dimana skor 8 mewakili kebimbangan/tekanan yang ringan. Tiada kaitan yang bererti diantara pemboleh ubah demogafi dan klinikal dengan kualiti hidup berkaitan visual dan tahap tekanan perasaan berdasarkan formula regrasi linear mudah dan berganda ($p > 0.05$ bagi semua pemboleh ubah yang diuji). Terdapat kaitan yang bererti diantara pemboleh ubah demografi dan tahap kebimbangan di mana $p < 0.05$ bagi umur, jantina perempuan, tempoh pemakaian mata palsu dan anoftalmia disebabkan oleh trauma. Skor kebimbangan berkurangan dengan setiap tahun peningkatan umur pesakit setiap tahun. Secara purata pesakit wanita mempunyai 1.49 mata lebih tinggi bagi skor kebimbangan berbanding pesakit lelaki. Pesakit yang telah memakai prosthesis melebihi 5 tahun memperoleh skor kebimbangan yang lebih rendah berbanding dengan pesakit yang baru setahun menggunakannya. Pesakit anoftalmia daripada punca trauma memperoleh skor kebimbangan

yang lebih tinggi berbanding mereka yang anoftalmia yang berpunca daripada tumor, jangkitan atau mata buta yang sakit.

Kesimpulan:

Kajian ini mendapati purata kualiti kehidupan pesakit berkaitan visual bagi pesakit dengan mata palsu selepas pembedahan *evisceration/enucleation* adalah berkurangan. Walau bagaimanapun, purata skor kebimbangan dan tekanan perasaan dikalangan pesakit ini adalah normal.

Tiada peramal yang berpotensi bagi kualiti kehidupan berkaitan visual atau tekanan perasaan. Peramal bagi tahap kebimbangan dikalangan pesakit anoftalmia dengan mata palsu yang berpotensi adalah jantina, umur, tempoh penggunaan mata palsu, trauma danpunca anoftalmia.

ABSTRACT

Introduction:

Patients with acquired anophthalmia post evisceration or enucleation surgeries are confronted with the loss of an eye as well as the pathological process which led to the surgery being performed. The regular use of prosthetic eyes in these patients has helped them to achieve a reasonable cosmetic outcome post operatively. Psychological sequelae of anopthalmia and prosthetic eye wear is often not addressed by the treating physician. Thus, identification of such sequelae may be helpful to these patients and others in the future so that they may referred to the appropriate channels for further evaluation.

Objective:

The aim of our study was to evaluate the levels of anxiety, depression and vision related quality of life in patients with prosthetic eyes post evisceration or enucleation and to determine the potential predictors associated with it.

Methods:

A cross sectional study was conducted between March 2017 and March 2018 involving patients with prosthetic eyes post evisceration or enucleation attending eye clinics of two tertiary hospitals in Malaysia; Hospital Selayang and Hospital Universiti Sains Malaysia.The patients were given two validated questionnaires: The National Eye Institute Visual Function

Questionnaire – (NEI-VFQ) and the Hospital Anxiety and Depression (HADS) questionnaire. After completion, the questionnaires were calculated and scored, and statistical analysis was done using Statistical Package for the Social Science (SPSS Inc Version 22).

Results:

A total of 54 patients with acquired anophthalmia with prosthetic eyes participated in the study. The demographic and clinical variables that were assessed were age, gender, race, marital status, highest education level, monthly household income, reason for enucleation/evisceration and duration of prosthesis wear.

The mean composite visual related quality of life was reduced with a score of 75.97. The minimum composite score was 18.75 and the maximum composite score was 100.

The mean HADS (D) depression score was 1.94 with a range of scores from 0 to 8. 53 patients had normal scores and only one had a score of more than 8. The mean HADS(A) Anxiety score was 3.61 with a range of scores from 0-10.48 patients had normal scores, and 6 patients had scores of more than 8. A score of more than 8 represents mild depression or anxiety. There were no significant associations between the demographic and clinical variables with vision related quality of life and depression levels based on the simple and multiple linear regression formulas ($p>0.05$ for all variables tested). There were significant associations between demographic and clinical variables with increased anxiety levels where $p<0.05$ for the variables of younger age, female gender, reduced duration of prosthesis wear and anopthalmia secondary to trauma. Anxiety scores decreased with every 1-year increase in a patients' age. Female patients had on average 1.49 points higher in anxiety scoring

compared to males. Patients with prolonged wear of prosthesis of more than 5 years had lower anxiety scores than those with less than 1 year of use. Patients with traumatic anophthalmia scored higher anxiety scores than those who acquired anophthalmia secondary to tumours, infections, or painful blind eyes.

Conclusion:

This study showed that the mean vision related quality of life scores in patients with prosthetic eyes post enucleation/evisceration was reduced however the mean anxiety and depression scores in these patients were within the normal range.

The predictors for increased anxiety levels in anophthalmic patients with prosthetic eyes was gender, age, duration of prosthesis wear, and the cause for anophthalmia. There were no potential predictors for vision related quality of life or for depression.

CHAPTER 1

INTRODUCTION

1.1 ANOPHTHALMIA

Anophthalmia is defined as the absence of the eye globe in the presence of ocular adnexa (lids, conjunctiva, lacrimal apparatus) which may be congential or acquired. (Verma and Fitzpatrick, 2007)

Congenital anophthalmia patients would present at birth or in childhood and is due to developmental anomalies which typically occurred in utero. Acquired anophthalmia may result either from evisceration or enucleations surgeries.

There are various indications for these destructive surgeries to be performed. Blinding ocular trauma which caused severe ocular damage and loss of ocular tissues which is irreparable, ocular malignancies requiring the eyeball to be removed to prevent further spread to surrounding structure, severe eye infections such as, panophthalmitis or endophthalmitis or perforated corneal ulcers which are not amenable to treatment and cases of painful blind eyes such as in neovascular glaucoma or pthyhsical eyes where there is loss of function are all common indications that warrant removal of the globe with or without surrounding structures.

The term ‘eye amputated’ has been coined to describe patients who have lost their eye following a surgery. (Rasmussen *et al.*, 2010; Roed Rasmussen *et al.*, 2009)

The decision to render a patient anophthalmic requires careful consideration and discussion between the physician and the patient as well as family members as it is a traumatic experience with potentially profound psychological sequelae.

After an evisceration or enucleation, a patient would have permanently lost the eye, some of their vision and a part of their face.(Rasmussen, 2010)

1.2.1 EVISCERATION

Evisceration is a surgical technique in which the intraocular contents are removed via a corneal, paralimbal or scleral incision. It is an ablative surgery. The contents that are removed include the retina, vitreous, lens and accessible uveal tissues, however the remaining sclera, Tenon's capsule, conjunctiva, extra-ocular muscles, and the optic nerve and its surrounding meninges are still preserved.(Chen, 2001)

This procedure was first reported in 1817 and was later modified to include an orbital implant into the scleral shell. (Deborah, 1999; Limbu *et al.*, 2009; Timothy *et al.*, 2003)

Routinely, the surgery is completed by including the placement of an implant into the evisceration cavity to maintain appropriate orbital volume. This may help to prevent the development of contractures of the orbital socket which will enable the use of an appropriate artificial (prosthetic) eye that will be both comfortable to the patient and not visibly apparent to the public.(Leatherbarrow, 2002)

The indications for evisceration are usually for functional or cosmetic purposes. It is a simpler surgery than enucleation and involves less orbital manipulation.Postoperatively,there is expected to be better ocular movements and less chance of enophthalmos as compared with enucleation.(Hansen *et al.*, 1999)

The ablative nature of the surgery consequently affects the anatomy and physiology of the orbital bones and orbital tissues which may affect cosmesis. A poor cosmetic result following surgery can have psychological implications for the patient the rest of their lives.(Odat *et al.*, 2012)

1.2.2 ENUCLEATION

Enucleation is a surgical procedure that involves removal of the entire globe and its contents, while still preserving the surrounding periorbital and orbital structures such as the lids and ocular adnexae.

It was first reported in the 1500s and later there were reports of implant insertion post enucleation, with the objective of preserving the orbital volume and preventing contracture of the socket.(Sami *et al.*, 2007)

The indications for performing enucleation are intraocular malignancy such as uveal melanoma or retinoblastoma, trauma, blind painful eyes, sympathetic ophthalmic and microphthalmos.

In cases of intraocular malignancy, enucleation is preferred as the intact globe and optic nerve can be sent for histological examination, and the margins of the tumour can be determined. It is also preferred in pthysical eyes as the shrunken scleral shell may not be able to accommodate an orbital implant if evisceration is performed.

It was found that there was no statistically significant aesthetic comparison between patients who underwent evisceration and enucleation, by both patients and masked observers.(Nakra *et al.*, 2006) .The same study found that that postoperative implant motility is reduced in enucleation as compared to evisceration, but that prosthetic motility was comparable between both groups of patients.

1.3 PROSTHETIC EYES

An artificial eye or ocular prosthesis does not provide vision, unlike a functional visual prosthesis or bionic eye (neural prosthesis that partially restore lost vision or amplify residual vision). It assumes the shape of a convex shell and replaces an absent eye following destructive eye surgery, such as evisceration or enucleation.

Modern prosthetic eyes were first introduced in 1944 when Murphy and Nirronen created physiologic ocular prosthesis in the dental corps of the United States Navy during World War 2.(Beumer *et al.*, 2011)

Prosthetic eyes are typically made of cryolite glass or medical grade plastic acrylic. They are available as readymade (stock) or custom-made prosthesis, the latter group more closely resembling the patients eye and being better fitted to the socket. Ocularists and occuloplastic surgeons usually manage the practice of fitting and managing prosthesis. Custom-made acrylic molds are molded based on the patient's enucleated/eviscerated socket. The prosthesis is molded and then hand painted to closely resemble the fellow eye.

Stock prosthesis is readily available in a few standard sizes, shapes, and colors and are not specially molded to fit the socket. The advantage of the stock prosthesis is that it can be used in the interim or immediately post operatively, or whilst awaiting a custom-made prosthesis. (Goel and Kumar, 1969; Kale *et al.*, 2008; Reis *et al.*, 2008; Smith, 1995)

Custom-made prosthetic eyes naturally are more superior to stock prosthesis as they allow for better ocular motility, have better fit and comfort, are less likely to cause ulceration and are able to adapt to the patients' facial contours. There is also the obvious advantage of greater aesthetics as it is designed to look like the fellow eye in terms of the pupil and iris size as well as the colour of the iris and sclera. (Artopoulou *et al.*, 2006; Beumer and Zlotolow, 1996; Ow and S, 1997). In addition, custom-made ocular prosthesis can provide close adaptation to the tissue bed whilst providing the wearer with maximum comfort and restoring the physiological function to the accessory organs of the eye.(Pun *et al.*, 2016) They can provide excellent cosmesis if they are fitted properly.

Common complications of prosthetic eyes are conjunctival irritation and discharge, giant papillary conjunctivitis, poor fitting and poor mobility. (Pun *et al.*, 2016)

In Malaysia, government hospitals provide services for ocular prosthesis; either by ocularists in certain centers with oculoplastic services, or by prosthodontic/dental departments. They are also available in certain private centers. In the government setting, both custom-made and stock prosthesis are provided free of charge. In private centers, one prosthetic eye can range from RM2800 to RM 7000.

The process of losing an eye has psychological effecst on a patient, hence a prosthesis should be provided as soon as possible for the comfort as well as psychological wellbeing of the patient.(Taylor, 2000)

Ideally, the psychological welfare of the patient should be evaluated prior to fitting and the nature of the ocular condition which led to the ablative procedure should be assessed, in the event of there being recurrence of the disease.(Cain, 1982)

1.4 ANXIETY AND DEPRESSION

Anxiety is a general term for several disorders that cause nervousness, fear, apprehension, and worrying. These disorders may manifest as physical symptoms and can also affect behavior and daily activities. The spectrum of anxiety may range from mild to severe which can severely debilitate a person and affect their daily activities.

Anxiety can be a normal response to a confronting a stressful situation, however if it begins to interfere and affect the individual's ability to function or to sleep, it may be distressful for the individual.

It has been postulated that anxiety is a problem for people with facial disfigurement. Macgregor described facial disfigurement as a 'psychological and social death'.The affected individual anticipates negative reactions from others and may become shy and defensive thus leading to social anxiety,lowered self esteem and social avoidance.(Macgregor, 1990) Anxiety could influence how people react to situations.(Lazarus and Folkman, 1984).It could also result in reduced usage of functional coping mechanisms.(Dropkin, 2001)

Anxiety disorders can further be classified according into more specific types using the *DSM-5,* the new edition of the *Diagnostic and Statistical Manual of Mental Disorders.* These

include common disorders such as General Anxiety Disorder, Panic Attacks and Panic Disorder.

Depression is one of the most common mental disorders worldwide.(Murray and Lopez, 1997) It is characterized as deterioration from previous function with the presence of psychological complaints such as depressed mood, loss of interest or pleasure, feelings of worthlessness or guilt and recurrent thoughts of death or suicide, together with somatic symptoms which include significant weight change, sleep disturbance, physical agitation or retardation, fatigue and inability to concentrate. (American Psychiatric Association, 2013)
In a Malaysian study, it was found that the prevalence of depression in Malaysia varied from 3.9 to 46%.(Mukhtar and P. S. Oei, 2011)

The Hospital Anxiety and Depression Scale is a simple but useful screening tool which can help clinicians to detect various states of depression and anxiety in outpatient clinics. (Snaith, 2003; Zigmond and Snaith, 1983)

1.5 QUALITY OF LIFE

The term "Quality of life" (QOL) is defined by the World Health Organization (WHO) as the subjective perception of well-being and wholeness. It is a broad concept that is affected in a complex way by the person's physical health, psychological state, and level of independence, social relationships, and their relationship with salient features of their environment.(Organization, 1947)

The assessment of health-related quality of life has been an important expansion of the assessment of the impact of disease and its treatment beyond the traditional areas of symptoms, signs, morbidity and mortality. It provides a more holistic assessment of the effects of disease on the person to include dimensions such as patient's physical, social and emotional well-being.

Quality of life also has health economic implications; more precise knowledge of the impact on quality of life will help determine the level of disease at which the benefit of screening outweighs the cost.

Vision-related quality of life (VRQOL) is related to visual function though it is not identical to it. VRQOL illustrates the extent to which vision impactsa person's ability to accomplish activities of daily living and encompasses an individual's social, emotional and economic well-being. VRQOL can be assessed by measuring the degree of impairment experienced in activities of daily living that rely on sight.(Angeles-Han *et al.*, 2011)

In adult patients, standardized visual function questionnaires in addition to clinical measures are used to assess visual disability using the National Eye Institute Visual Function Questionnaire – (NEI-VFQ).(Mangione *et al.*, 2001).

1.6 RATIONALE OF STUDY

Previous studies have demonstrated that there is some level of anxiety and depression as well as a decreased vision related quality of life associated with having an ocular prosthesis.(Ahn and Lee, 2010; McBain *et al.*, 2014; Ye *et al.*, 2015).The major cause for this was due to the poorer vision related quality of life as well as due to concerns with facial appearance. Facial appearance was found to be an important factor on how they felt they are viewed by society at large and weather they felt discriminated.(McBain *et al.*, 2014)

Poor Vision related quality of life in anophthalmic patients is associated with monocular vision causing difficulties in performing daily activities and working while as many as 26% of patients reporting to having pain, which is a part of the phantom eye syndrome.(Ye *et al.*, 2015)

The psychosocial and demographic variables were related to living arrangements (not living alone) and having adequate support from family and friends.(McBain *et al.*, 2014) Other variables which had positive indicators were age, where younger ages were found to be more anxious as well as lower levels of education.(Ye *et al.*, 2015).Conversely, in another study it was found that higher age, marriage and female gender were more associated with a greater negative impact on quality of life.(Song *et al.*, 2006)

It was found that 29.9% and 28.4% of anophthalmic patients obtained a score ranging from 8-21 on the HADS-A and HADS-D questionnaires respectively, which was comparable with the percentages seen in patients with other chronic diseases such as heart disease and cancer.(Ahn and Lee, 2010)

In the study by McBain et al, the HADS questionnaire was used as a screening tool to measure levels of anxiety and depression in patients with prosthetic eyes. The mean scores for both anxiety and depression were within the normal range, however 18% of patients were suffering from clinical anxiety and depression.(McBain *et al.*, 2014)

In a study by Kondo et al., the NEI VFQ 25 as well as the Medical Outcomes Study Short Form 12, were used to assess vision and general health of anophthalmic patients as well as anxiety and depression.(Kondo *et al.*, 2013)

Studies assessing the psychosocial impact of acquired anophthalmia and ocular prosthesis has been conducted in many countries. Vision related quality of life and levels of anxiety and depression in Malaysian patients with acquired anophthalmia and prosthetic eyes has not been assessed before. The psychosocial impact of ablative eye surgery and fitting with prosthetic eyes in Malaysian patients has not been considered or routinely assessed and followed up. There is a possibility that some patients may need counselling, behavioral therapy or a psychiatric referral which is being overlooked by ophthalmologists.

The rationale of this study is to investigate if there is indeed reduced vision related quality of life and increased levels of anxiety and depression and the demographic variables related to them, in the context of Malaysian patients with prosthetic eyes.

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CHAPTER 2

OBJECTIVES OF THE STUDY

2.0 STUDY OBJECTIVES

2.1 GENERAL OBJECTIVES

To evaluate the psychological effect and vision related quality of life in enucleated/eviscerated patients with prosthetic eyes

2.2 SPECIFIC OBJECTIVES

2.2.1

To determine the mean NEIVFQ-25 scores in patients with prosthetic eye using a single mean formula in 2017-2018 in Hospital Selayang and Hospital Universiti Sains Malaysia

2.2.2

To determine the mean Anxiety and Depression (HADS) scores in patients with prosthetic eye using a single mean formula in 2017-2018 in Hospital Selayang and Hospital Universiti Sains Malaysia

2.2.3

To determine the potential predictors of NEIVFQ-25 & HADS(Anxiety), HADS(Depression) scores in patients with prosthetic eye using a multiple regression formula in 2017-2018 in Hospital Selayang and Hospital Universiti Sains Malaysia

CHAPTER 3

MANUSCRIPT

EVALUATION OF THE PSYCHOLOGICAL EFFECT AND VISION RELATED QUALITY OF LIFE IN ENUCLEATED/EVISCERATED PATIENTS WITH PROSTHETIC EYES

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3.1 ABSTRACT

Background:

Patients with acquired anophthalmia post evisceration or enucleation surgeries are confronted with the loss of an eye and their vision.The aim of our study was to evaluate the levels of anxiety, depression and vision related quality of life in patients with prosthetic eyes post evisceration or enucleation and to determine the potential predictors associated with it.

Methods:

A cross sectional study was conducted between March 2017 and March 2018 involving patients with prosthetic eyes post evisceration or enucleation attending eye clinics of two tertiary hospitals in Malaysia; Hospital Selayang and Hospital Universiti Sains Malaysia.The patients were given two validated questionnaires: The National Eye Institute Visual Function Questionnaire – (NEI-VFQ) and the Hospital Anxiety and Depression (HADS) questionnaire. The questionnaires were calculated and scored and descriptive statistical analysis was done using Statistical Package for the Social Science (SPSS Inc Version 22). & STATA version 14 software (StataCorp., 2015) for Multiple Linear Regression analysis.

Results:

A total of 54 patients participated in the study. The mean composite visual related quality of life was reduced with a score of 75.97.

The mean HADS (D) depression score was 1.94.The mean HADS(A) Anxiety score was 3.61.There were no significant associations between the demographic variables with vision related quality of life and depression levels.There were significant associations between the demographic variables and anxiety levels where $p<0.05$ for age, gender, duration of prosthesis wear and reason for prosthesis based on multi linear regression analysis.

Conclusion:

This study showed that the mean vision related quality of life scores in patients with prosthetic eyes post enucleation/evisceration was reduced however the mean anxiety and depression scores in these patients were within the normal range.

The predictors for anxiety levels in anopthalmic patients with prosthetic eyes was gender, age, duration of prosthesis wear, and cause for anophthalmia. There were no potential predictors for vision related quality of life or for depression.

Keywords:

Prosthetic eyes; quality of life; evisceration; enucleation