THE ROLE OF THE OPHTHALMIC NURSE COUNSELLOR

LOUISE DE BOARD AND *JASMINE THOMBS* DESCRIBE THEIR WORK WITH PATIENTS UNDERGOING REMOVAL OF AN EYE AFTER TRAUMATIC INJURY

'I'll be disfigured for life,' said Wendy, a patient facing removal of the eye.

In the UK, it is estimated that almost two million people are affected by sight loss. This number is expected to double by 2050[1]. Moorfields Eye Hospital NHS Trust is the UK's largest ophthalmology centre. Established in 1804, it provides primary, secondary and tertiary eye care for patients from the London area and all over the UK, and is renowned for the excellence of its treatment, its teaching and its research into eye diseases. The number of people attending outpatient clinics (including satellite clinics) at Moorfields in 2012/2013 was 415,209, the number attending A & E was 82,435, and the total for inpatients and day case admissions was 31,180[2].

In this article, we will refer to the multiple aspects of the ophthalmic counsellor's role in supporting patients facing removal of an eye (evisceration/enucleation surgery) as the result of traumatic injury. We will also look at patients' possible reactions to trauma, and at the effect of trauma on psychological processes.

Although this article considers the role of ophthalmic nurse counsellors, it should be recognised that, before being referred to the nurse counsellors, the pre-surgical patient will have seen members of the Adnexal team at Moorfields Eye Hospital including consultants, nurses and clinical nurse specialists, all of whom have advanced levels of communication skills. It is also important to note that the experienced and skilled technicians in the Ocular Prosthetic department will spend many hours working with patients and supporting them to obtain optimum cosmetic results.

The role of the ophthalmic nurse counsellor supporting patients facing evisceration/enucleation surgery as the result of traumatic injury can be complex, and consists of multiple aspects. In addition to offering psychological support and counselling, the ophthalmic nurse counsellors also provide patients with information where appropriate. This can be somewhat unusual in a counselling role as we know counsellors do not usually give advice. Patients are assessed on their need, desire and capacity for information. Pre-surgery, this may involve giving written information and providing DVDs. This information will detail the surgical procedure and pre and post-operative care, as well as giving contact details for relevant hospital staff and relevant external agencies and helplines. In the internet age, patients will often surf many websites and it can be helpful to signpost to reputable sites. Frequently asked questions may include those relating to the length of time in hospital, pain management, possible cosmetic result, and the length of time until the prosthesis (artificial eye) will be fitted.

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Following assessment, the nurse counsellors will also show patients prosthetic eyes and conformers (clear plastic shells used to provide protection and shape to the eye socket) and encourage patients to handle them. This process may go some way to helping patients to overcome fears about prostheses. Often the fear of the unknown is the most difficult aspect, and literally touching the prosthesis can help patients to 'handle' the reality.

EXAMPLES OF OUR WORK WITH PATIENTS

Below are two case examples demonstrating how ophthalmic nurse counsellors work with patients.

A 60-year-old man was discussing his forthcoming enucleation surgery. He had attended two previous counselling sessions and the counsellor was very aware that he had not spoken of the traumatic event that had caused his injury. When she asked him how his injury happened, there was a long silence before he answered very quietly and told her about the incident that had happened when he was at school. He described how another child had accidently hit him in his eye with a stone. He was tearful after he described this and said that it was the first time that he had spoken about it in detail. He went on to say that perhaps the most difficult thing was that his parents would never refer to the accident or let him speak about it. He talked at length about how hard this had been and how angry he felt with his parents about not letting him talk about what happened. At first, he said that he felt that his parents were angry or ashamed of him. However, at the next session, he said that he had been thinking about why his parents would not speak about the accident and that he had come to believe that the reason was that they 'could not bear my pain'. He was emotional as he spoke of this and it felt like a significant moment in the therapy, as if perhaps something was moving or becoming unstuck in the memory of the trauma.

Sue, a woman in her 20s, came to her first session in a distressed state. She explained that her fear was not related to her actual surgery as she had undergone many previous operations on her eye. She was, however, terrified at the prospect of inserting an artificial eye as she felt sure that she could not cope with the process and the thought of it filled her with fear. In the counselling session, she spoke of her fears and, with her agreement, was shown some prosthetic eyes, which she looked at and gradually handled, becoming more familiar with the prosthesis and less anxious. This session helped her to overcome some of her fear.

TRAUMA AND PSYCHOLOGICAL PROCESSES

'Patients increasingly expect to receive counselling, particularly when facing traumatic surgery'.[3] The psychological reactions to trauma are well documented.

Most patients experience feelings of anxiety, helplessness, hopelessness, and guilt; these are often compounded by insomnia, anorexia, irritability, inability to concentrate and depression[3].

The patients we are considering in this article have undergone injury to their eye as a result of trauma. Van der Kolk and Fisler[4] define a trauma as an inescapably stressful event that overwhelms people's existing coping mechanisms. They describe traumatic memories as a form of mental imprint with sensory and affective (ie thinking and feeling), elements to the memory[4].

The *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)* recognises that trauma can lead to extremes of retention or forgetting. This means that traumatic memories can be remembered with extreme vividness or resist integration. As a consequence, at times, the traumatic memories may not be forgotten. When Viktor Frankl, a concentration camp survivor, wrote of reaction to traumatic events, he stated that: 'An abnormal reaction to an abnormal situation is normal behaviour.'[5] Often, when working with patients who are facing eye removal, the description and narrative of the original trauma can appear very clear and immediate. Indeed, when counselling pre-surgical enucleation patients, the sense of the traumatic memory, having been frozen at the time of the trauma, is often very strong. A 70-year-old patient vividly described the industrial accident that had resulted in her eye injury. I asked when the incident had occurred and was surprised to hear that the original traumatic injury had happened over 30 years ago. She was describing it with such immediacy that I had assumed that it had happened a matter of months ago. Another patient's eye trauma was the result of being shot in the eye when he was a six-year-old child. He still thought of the incident on an almost daily basis. He described how, as a result of this traumatic event, he had become phobic of tall buildings, fearing snipers.

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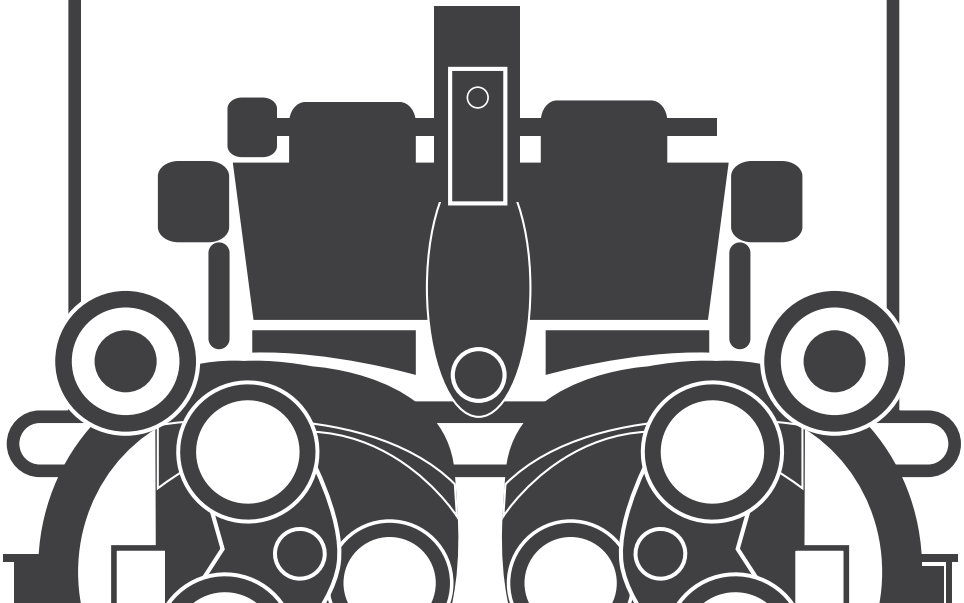

As counsellors, it is particularly important that we have an awareness of the psychological processes involved when working with traumatised patients and that we are conscious that there is a risk of patients becoming retraumatised. We are careful to work with patients at their pace and we are guided by them concerning the amount of information that they may choose to disclose about their injury. We are also mindful of the fact that some patients may not wish to disclose information or engage in the counselling process; in these cases, our role is about support and information-giving.

STIGMA

Many patients affected by traumatic eye injury describe 'feelings of stigma'. Patients often speak of feelings of shame and of an inability to disclose, or to speak of, their eye problems. In his 1963 book, *Stigma: notes on the management of spoiled identity*, Goffman[6] defines stigma as 'a trait which is deeply discrediting'. He makes clear that stigmatisation is an interactive social process. More recently, authors have used the term stigma in a wider sense to refer to the reaction of other people. Scambler[7], for example, describes two types of stigma: 'felt' stigma and 'enacted' stigma. He first developed these ideas in relation to his work on epilepsy.

'Felt' stigma, also known as internal stigma, refers to the shame and expectation of discrimination that prevents people from talking about their experiences and stops them seeking help. Felt stigma is the product of the internalisation of shame, blame, hopelessness, guilt and fear. Indeed,

many pre-evisceration/enucleation patients speak of feelings of guilt about their eye injury, and some speak of feeling that they are being punished for some unknown wrong.

From our experience as ophthalmic counsellors, we know that the effect of traumatic eye injury often affects perception of self. The concept of beauty is very important in our society today. Frequently, the media negatively stereotype people who have undergone eye loss. In literature, eyes are often portrayed as emblems of perception and perspective, for example, as entryways to the heart. During our clinical work, many patients quote from Shakespeare's *A Midsummer Night's Dream*: 'The eyes are the windows to your soul'. One 40-year-old man with a phthisical eye that was opaque in appearance, said: 'If your eyes are the window to your soul, then I worry about what this says about me and what it says about my soul.'

'Enacted' stigma, also referred to as external stigma, refers to the experience of unfair treatment by others. Enacted stigma can obviously be damaging since it leads to withdrawal and restriction of social support. Patients who have lived with eye disfigurement for many years have often developed various ways of disguising their affected eye. Often these behaviours are a result of their experiences of the reactions of others. Some coping mechanisms may include wearing very large sunglasses, peaked caps, and hairstyles that will disguise the affected eye. Coping mechanisms, however, can ultimately increase rather than decrease symptoms. The process is similar to social withdrawal in somebody with a fear of social situations – their avoidance makes their fear worse in the long term.

Frequently, patients speak about their particular difficulties with eye contact. Many describe finding it very hard to maintain eye contact and have developed the technique of looking downwards. Patients also talk of the negative effect that this can have on relationships and self-esteem. The charity Changing Faces, which works with adults and children who have facial disfigurement, provides specific information on coping with disfigurement and describes the importance of eye contact in communication[8].

THE PSYCHOLOGICAL IMPACT OF SYMPTOMS

At times, it can be hard to fully understand the possible psychological impact of symptoms relating to traumatic eye injury. For example, the clinical definition of a damaged eye that may have become shrunken and may bleed does not always convey the psychological impact of living with a phthisical eye. A graphic illustration of this can be seen in the example of a 64-year-old man waiting for eye removal surgery: he was experiencing bleeding from the eye, a symptom that he found very upsetting. He had gone to a Catholic school and was haunted by religious statues with stigmata. For him, the fact that he was crying tears of blood took on some form of religious symbolism, and he said, 'This is like my own crimson stigmata'. He found the experience very distressing and said that it was hard for him to convey the psychological impact this was having on him.

SUMMARY

It is clear that this group of ophthalmic patients need a great deal of time and emotional support. Creating the opportunity to talk and to express emotion is essential to the delivery of good care and should be made available throughout the patient's journey.

The counselling role is now an integral service offered to all ophthalmic patients attending Moorfields Eye Hospital. In particular, the service offers counselling for those who are distressed and acutely traumatised by their eye condition. In the UK there are only a few hospitals where ophthalmic patients are offered any form of counselling, and there are certainly many more patients who could benefit

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DEFINITIONS

Enucleation – surgical removal of the eye only: the eyelids, lashes, brow and surrounding skin are all left intact.

Evisceration – complete removal of the contents of the eye, leaving the white part of the eye (the scleral sac) which has the muscles still attached.

Phthisical eye – a damaged eye that has become shrunken.

READER RESPONSE

The authors welcome feedback on this article. To contact Louise, please email louise.deboard@moofields.nhs.uk and to contact Jasmine, please email jasmine.thombs@moorfields.nhs.uk. To contact the journal, email hcpj.editorial@bacp.co.uk.