

Psychological complexities of visual restoration

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SUMMARY

In this paper, we report the psychological and emotional experience of a patient who regained vision after over a decade of vision loss. The negative psychological implications of blindness are well recognised and there is a robust link between visual impairment and low mood and depressive symptoms. Although uncommon, low mood and depressive symptoms have been reported in patients whose sight has been restored, and lack of research gives rise to the possibility their prevalence may be grossly under-recognised in such patient groups. The effects can be so severe that patients may revert to living in darkness in mimicry of their previous lifestyle, effectively obviating the sight-restoring surgery. Healthcare professionals have a responsibility to address this traditionally neglected need by facilitating social, psychological and medical interventions that may ease the return to vision.

BACKGROUND

The National Federation of the Blind defines blindness as 'vision loss which severely interferes with daily functioning' and usually requires the use of alternative methods to accomplish routine as well as work-related tasks. Society regards blindness as a tragic and functionally disabling impairment, however minimal attention is directed towards resulting psychological distress, despite this being interwoven with functional decline. The literature documents robust links to reduced physical and social activity, and increased loneliness and depression. All of these factors may contribute to a reduction in well-being.²³ Psychological distress may also impact physical recovery, as psychosocial difficulties have been shown to be related to poor recovery from surgery in different populations.^{4 5} Anxiety and depression have been shown to increase the experience of postoperative pain, and psychological stress has been shown to contribute to a negative effect on wound healing and immune function. ⁶⁷ As the capabilities of ophthalmological interventions and novel therapies advance, the relevance of the psychological implications of vision restoration will become increasingly wider.

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CASE PRESENTATION

Preoperative impact

This patient presented to the ophthalmology department at the age of 32 years, with bilateral atopic cataracts and chronic keratoconjunctivitis. He subsequently underwent right eye cataract surgery and lens implants, which led to improvement of his vision. Aged 35 years, he underwent left eye cataract surgery. His vision in the left eye was completely lost due to postoperative endophthalmitis. His right

eye slowly deteriorated due to corneal changes, and by the age of 39 years, his vision had reached the stage where recognising faces became challenging. Aged 42 years he had to give up driving, although his vision remained sufficient to read, and he was thus able to continue working until the age of 47 years. He then took early retirement on the grounds of his failing vision and was registered legally blind; however, he made a concerted effort to continue working 2 days a week.

He found his visual loss resulted in significant withdrawal from activities and social interactions that he previously enjoyed. He illustrated a degree of acceptance that he was going blind, commenting, "My standard comment to sympathetic enquiries was that I felt that I had been fortunate in that the deterioration in my sight had taken place slowly over a long period of time, thus giving me time to adjust to it." By the time he reached the age of 54 years, his right eye's vision had deteriorated to the extent that it became impossible to navigate safely around an unfamiliar location.

Postoperative impact

At 56 years old, full penetrating keratoplasty was performed on his right eye with immediate success, and his visual acuity improved to the point of being able to distinguish the folds in the sleeve of the optometrist's coat. He was able to see simple objects previously unseen for 15 years, recognise the faces of loved ones and even to read with a magnifying glass. Once the initial euphoria subsided however, he found re-establishing himself in a sighted world more of a challenge than one would perhaps expect, and these challenges were multifaceted. Initially for example, he found scanning the environment to look for hazards that did not come naturally and required active concentration.

Social difficulties also awaited him, he struggled to reacquaint himself with the subtlety of the unwritten rules of eye contact, which left him struggling with some social interactions. He also found that he often had to be reliant on people's voices to recognise them, and was embarrassed to not be able to recognise some people by sight. He reported a lack of confidence in social interactions even after a year had passed. He also reported difficulty in contending with the discrepancy between the mental pictures of his wife and close relatives that he had previously relied on and the current reality, while he was additionally faced with a very different picture of himself in the mirror to the one in his memory. Furthermore, he expressed a conflict between the perceptions and expectations of others as to his recovery and the reality of his actual abilities, which he termed 'desynchrony'. Invariably his recovery moved at a slower pace than perhaps

others would expect of him, with some aspects of his previous sighted life never being totally reclaimed. Despite having his sight restored at the relatively young age of 56 years, he did not return to work, stating that he did not feel able to come out of retirement. By the time his sight was restored he had not driven for approximately 15 years, and due to a lack of confidence did not return to driving, despite the practical benefits it would have afforded him. The implications of this patient's experiences and that of the psychological challenges of vision restoration will be discussed here.

TREATMENT

We did not provide any specific treatment for the psychological issues we discuss.

OUTCOME AND FOLLOW-UP

The patient reported ongoing psychological, emotional and practical difficulties readjusting to sighted life.

DISCUSSION

Vision is considered by many to be their most valued sense, and the loss of other senses such as smell is considered less disabling and to have less of a psychological impact, as they often require a less overwhelming alteration of one's life plan. From the onset of decline in visual function, a period of psychological turbulence commences as individuals begin to realign their lives around harnessing the prized sight that remains.

A psychological perspective on vision loss

The Mehrabian 7-38-55 rule underpins the complexity of communication and suggests that words provide only 7% of communication cues between individuals, intonation provides 38% and body language provides 55%. Therefore, an individual who has lost their sight has lost over half of their cues in interpreting conversation and social situations. Adams and Pearlman postulate there are three possible responses to sight loss: acceptance, denial or depression, with acceptance of vision loss specifically linked to better adjustment. Our patient felt the acceptance he illustrated of gradual deterioration in his vision improved his quality of life.

A number of risk factors, including poor social support and living arrangements, poor general health and higher levels of neuroticism, have been identified as potential predictors of depression following vision loss. ^{11–13} Dependence and enforced change in lifestyle and ambitions are potential fuels for low mood states. It is often assumed that most challenges will arise from loss of function secondary to loss of sight; however, an equally significant barrier may be that of the thinking patterns, mental barriers and change in identity created by the impairment. ¹ It is unsurprising therefore that social isolation and low mood is a common sequel of vision loss. Low mood may be further compounded by (literal or perceived), inaccessibility to support and resources for managing depression resulting from vision loss. ¹⁴

Despite the significant difficulties facing those afflicted by visual loss, healthcare professionals are in a position to ease this transition through appropriate counselling, clear communication and recognition of depression by active listening processes.

Psychological perspective on vision restoration

The psychological and emotional trauma associated with visual loss is well documented, and visually impaired people often lose confidence and independence, coming to rely on family members and other agencies like social care workers. The problems associated with regaining vision, however, are less well recognised. The restoration of sight may increase opportunities yet confer new responsibilities, and societal obligations and requirements may change significantly.

When sight is regained, the return of confidence and regaining of independence will require time and adjustments, and an element of dependence on others often remains. Perhaps most difficult in this readaptation is the social communication associated with sight. Visual cues play a significant role in speech intelligibility, and visual impairment may hinder speech reading. As previously discussed, Mehrabian theory suggests that loss of vision leads to a 55% loss in communication during conversation; restoration of vision therefore facilitates a perhaps overwhelming 122% increase in visual sensory communication input and capabilities, skills that have waned during blindness and need to be relearnt. Difficulties include the reported struggle to reacquaint oneself with eye contact as reported by our patient, and individuals risk humiliation and embarrassment when for example they cannot reliably recognise faces some time after regaining sight and require the security of recognising their voice. Therefore, for many patients, despite the precipitating factor of vision loss being removed social isolation continues, as in this patient's case, and can sustain a low mood state. 14 1

As blind individuals adapt to the loss of vision by relying on other senses, these become more authoritative and trusted in comparison with those of sighted individuals. This may partly explain why on restoration of vision some individuals exhibit difficulties in trusting their new unproven sense. Visual-cue-dependent neural networks may become redundant during the visual deprivation, and adapting to new visual cues to judge perspective in terms of distance and depth can take time. Processing the visual input and cues from the newly reacquired sense can be daunting, and sensory input normal to a sighted individual can be overwhelming to an individual who has regained sight after a lengthy period.

Further, as with our patient, the newly vision-restored patient must make a tremendous effort to reconcile the newly acquired visual input with their finely honed and sometimes conflicting auditory input. In his book 'Eye and Brain', psychologist Richard Gregory described a young adult who gained vision that was lost during his childhood. He experienced difficulty trusting his newfound vision to cross the road unaided by his white cane and became terrified to cross the road even with helpers around him. 16 This lack of trust in visual sense often results in individuals tending to remain tactile, feeling the need to feel objects and environments due to greater familiarity with this sense. Indeed, when an unfamiliar object was shown to one individual who had his vision restored, he palpated it with eyes closed then stated, "Now that I've felt it I can see it." In some cases, patients who had poor vision during early life have reported that restoration of vision later in life caused distress related to the number of imperfections in the world. A lack of vision may possibly instil ideas of a world which subsequently cannot meet expectations, with cosmetic irregularities causing great distress. 16

Secondary gain in vision loss and restoration

Secondary gain can be an important factor to consider in the context of chronic conditions, as these benefits may encourage perpetuation of disability and illness behaviour.¹⁷ The literature evidences little evidence of this being a factor in vision loss or restoration however, and we did not feel it to be a factor with our patient. Although it could be argued that he received

secondary gains such as reduced responsibility and disability benefits due to blindness, it is clear that the prospect of sight restoration outweighed these hypothesised gains. In terms of his emotional and psychological difficulties post-surgery, we were unable to follow up for long enough to explore secondary gain, although we could find no evidence that this was a factor in the reporting of his emotional and psychological difficulties.

Role of healthcare professionals

The issues discussed highlight the degree of complexity involved in the psychological adaptation to restoration of vision, and suggest that highly tailored strategies to address individuals' needs will be more appropriate in addressing these than standardised packages of care. The literature documents that in some extreme cases, patients struggle to readapt to sighted living to the point that they revert to living without light, obviating the effects of the vision-restoring surgery and potentially reducing their overall quality of life. The role of healthcare professionals has several facets and is multidisciplinary, relating to preoperative care, occupational therapy and psychological input.

Following the principle of 'Prevention is better than cure', we propose additional focus should be placed on the preoperative phase of the patient's journey. Managing expectations is a crucial aspect of preoperative care, and clear communication is paramount to this. Preoperative care should aim to prepare the individual and manage their expectations to ensure that they are realistic and informed about the potential outcomes and complications of surgery. While failure of vision restoration will be clearly cited as a potential complication of surgery, we propose that the potential psychological implications of vision restoration should also be included in the consent and preoperative care process.

In the patient we discuss here, preoperative counselling was given according to current guidelines and confined to potential physical complications such as corneal transplant rejection and transplant failure, that may result in vision loss. As we did not anticipate the potential psychological complications of vision restoration these were not outlined to the patient, and no preoperative or postoperative psychological tests were administered. We have subsequently modified our preoperative counselling and consenting process, and in addition to explaining the known potential benefits and risks of surgery, our preoperative counselling now includes outlining the potential psychological and emotional difficulties that can ensue following restoration of vision. This is particularly emphasised in cases where vision has been lost for a considerable length of time. Moving forward, we suggest that ophthalmology clinics can administer psychological measures that examine constructs such as well-being, anxiety and depression pre-surgery and post-surgery, in order to generate quantitative data and inform further treatment. Should these difficulties occur, a referral to secondary mental health services or directly to a clinical psychologist can be recommended.

Psychological support should encompass interventions that enhance resilience and provide opportunities for enhanced access to social support and, where possible, foster social integration. This, in combination with occupational therapy that focuses on the practicalities of adaptation to sighted life and offers support to keep active, will enable the provision of a holistic support package appropriate for individuals as they readjust to the unfamiliarity of sight.

Rehabilitation should be flexible enough to support the individual to adapt at their pace, and care should be taken to avoid placing unrealistic expectations on patients. We speculate that

the longer the individual was blind, the lengthier and more difficult the rehabilitation process may be. Our patient felt that he was very conscious of the expectations of others to return to 'normal' sighted living and suggested that these expectations may have been even more prominent if he were not retired and with minimal social commitments. He speculated that some individuals might feel guilty on sight restoration if their adaptation is not instant and seamless; perhaps perceiving that slow progress is not appreciating this sudden gift of sight they have unexpectedly received. Readaptation to sighted life is a process that some patients may especially struggle with if their mental health worsens, and they may benefit from the consistent presence of postoperative psychological support. This may assist in reducing the incidence of acute deteriorations in their mental health and minimising large deleterious fluctuations in their recovery. A specialised rehabilitation programme is therefore recommended. the effectiveness of which will likely be further increased when it follows an integrative biopsychosocial approach.

To summarise, psychological distress following vision-restoring surgery is multifactorial, and while extremes of these difficulties may only be observed in the minority of patients, this case highlights the relevance of addressing the psychological issues involved, as otherwise such pioneering successes of medicine in vision restoration may fail to improve quality of life for the patient.

Conclusion

There will be many more patients like ours, whose lives will be transformed by advances in ophthalmology. With the advancement in science and technology in areas of gene therapy, stem cell research, regenerative medicine and novel biological agents, in the future vision restoration may become possible in more individuals who have lost their sight for lengthy periods of time. It is essential that healthcare professionals involved understand not just the visual neuroscience and physical health issues for patients, but also the full spectrum of complex psychosocial issues surrounding reinstatement of vision. The potential psychological, emotional and mental upheavals warrant further research in order to more effectively anticipate and treat them.

Learning points

- ► Regaining of vision after a lengthy period can bring about unexpected emotional and psychological upheavals.
- ➤ During preoperative care for vision-restoring surgery, patient should be educated not just on the risk of failure, but also of the possible complexity of success.
- ▶ Preoperative and postoperative tests may be administered which examine psychological constructs such as anxiety and depression; these will allow us to explore the psychological elements of vision restoration.

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