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Coping with Visual Impairment: Helping our Patients Face the Truth

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Abstract

This chapter explores the factors influencing patients' ability to cope with imminent visual impairment (blindness) as well as methods that can be used to aid patients to rid stereotypes associated with their visual impairment. The factors that influence a patient's ability to cope with blindness can stem from both biological and social backgrounds; biological as it relates to age and social, meaning individuals that are in contact with the patient on a daily basis. Older patients tend to have more difficulty coping with blindness because they have established norms while children tend to feed of their parents' view of their visual impairment. Some patients practice a more spiritual approach to coping with their visual impairment. Although studies have been inconclusive; patients who pray and practice faith tend to have a more positive attitude towards their situation. Participating in sports can also help the visually impaired to have a more positive attitude towards themselves.

Keywords: visual impairment, blindness, coping, spiritual perspective, age

1. Introduction

Eye care professionals are faced with the formidable challenge and responsibility of being the voice of hope or doom for persons who desperately seek to cling to their last bit of vision. The history behind vision rehabilitation and integration of the visually challenged into society is an area of particular interest worthy of global collaboration [1]. The history of blindness, is a growing and now fashionable area of historical interest chronicled back to biblical era. The outlook has survived the mythological and demonic perspectives, thanks to science, and notable writers such as Helen Keller, John Milton and Louis Braille. While medical science

has unveiled the mysteries behind congenital conditions such as leber congenital amaurosis, glaucoma and its management, and the myriad of systemic diseases associated with degrees of avoidable vision loss; there is still great need to dispel myths about visual impairment.

Mills [1], attended a world conference on the history of blindness and listed some areas of discussion which summarizes historical perspectives and their evolution. The disciplines ranged from history, science, philosophy, medicine, social studies, religious history, to literature, art, and psychoanalysis. Papers included 'Different Ways of Seeing in the Middle Ages', 'Blindness, Learning and the Politics of Radio in Interwar France' and 'What a Blind Man Saw at the International Exhibition of 1862.

Visually impaired C. Kudlick, PhD (July 26, 2015) posited in an interview that most people think of disability as a biological, physiological thing that happens to someone, something ahistorical, rather than an identity shaped by history, politics, economics, society, and culture. She is now leading a charge to have the history of disability be a recognized field of study.

In line with the historical perspective of visual impairment, someone deemed as visually impaired often is condemned to a life of confinement and would not be deemed as 'valuable' to society, which often deters the coping process for patients due to lack of self-esteem. Therefore society plays a vital role in a patient's coping ability. Age also plays a vital role in the coping process, as older patients tend to have a harder time coping with their visual impairment. There are different methods for coping with blindness which will be discussed further in this chapter. Technology has over the years evolved and has helped doctors immensely in their prognoses and further help with 'breaking the news' of imminent blindness. Visually impaired patients can integrate into society and regain independence with help of a patient doctor and having accepted and adapted to their new way of life.

2. Age and its effect on adaptability

A paper-review study [2] found seven main areas impacted by vision impairment in adults over 60. These areas include: depression or mental health, anxiety, quality of life or well-being, social functioning, loneliness, or social support and interventions. It was concluded that most of these areas listed previously directly correlates to vision impairment (**Table 1**).

Older persons who have formed habits, and established norms will be more challenged by the impact on their lifestyle by impairment of vision function; some patients even remarking a preference for vision than any of the other senses. Many of my own patients remark they would rather deafness or even death itself, to blindness. Congenital and early onset vision impairment is less likely to lead to negative psychological outcome, and adaptability is more likely.

The attitude of parents towards their visually impaired children has a direct relationship to their child's acceptance of visual impairment. The attitudes range from shock and despondence, later to acceptance, overindulgence, overprotection, then comes the phase of hope in what medicine can do through the ophthalmologist. Parents have the opportunity and ability to mold the child in a positive attitude, and later acceptance by wider society.

Areas	Implications
Depression or mental health	Older people with vision loss are more at risk of reporting symptoms of depression and lower mental health, and being diagnosed with clinical depression than their sighted peers. Visual functioning rather than vision status has a stronger relationship with depressive symptoms.
Anxiety	Anxiety is not more prevalent and quality of life was not consistently reduced in persons with visual impairment.
Social functioning and Quality of life or well-being	Social functioning is likely to be reduced in individuals with vision loss, but not social network size or social activity.
Social support	Social support buffers against the presence of depressive symptoms but there is mixed evidence for social support to facilitate adaptation to vision loss and psychological well-being.
Loneliness	Loneliness is under-researched but one study suggested a higher prevalence of mild loneliness in individuals with vision loss.
Interventions	Interventions that address psychosocial needs directly are more effective than rehabilitation that addresses them indirectly through instrumental support.

Table 1. Conclusions drawn from paper-review study.

Parents initiate negative reactions based on their hopes and dreams of a normal child. Their social anxiety, which is fuelled by the embarrassment about the child's disability, is transferred to the child who likely feels differently. Simple activities like dressing, feeding, hygiene practices, play and study become a major problem from a parenting perspective. The fear and anxiety borne out of this parental attitude is what causes the child to experience the same in their interaction with their peers. Parents play an important role in stimulating a child's interest in his or her surroundings. Children become bored easily when the visual stimulus is withheld, hence parents must find alternative ways to drive the child's interest. "Remember that curiosity and desire are the two eyes through which a person sees the world in its most enchanted colors" [3].

In planning the approach to counseling visually impaired persons, due diligence has to be given to those caring for them: their family members, loved ones, co-workers, and friends. Acceptance from family and the wider society is crucial to self-acceptance when considering physical disability. While parental attitude is critical in children, the attitude of adult support systems is important to adults facing visual impairment.

3. Breaking the bad news

Psychologists agree that the approach by a professional such as an Ophthalmologist in breaking the news of imminent visual impairment or eventual blindness is not unlike that for terminal illness or death; hence the phases of adjustment are similar [4]. The seven phases of adjustment to blindness are: (1) trauma (physical or social), (2) shock and denial, (3) mourning and withdrawal, (4) succumbing and depression, (5) reassessment and reaffirmation, (6)

coping and mobilization, and (7) self-acceptance and self-esteem [5]. The duration and outcome of the stages are unpredictable. The social and relational factors discussed in the previous section are among others that will influence the sequence.

Professionals must stress the positive in all situations, and outline to family members that all aspects of vision must be appreciated and respected. While 20/20 to 20/40 may be the gold standard to function vocationally in everyday life, many will come to appreciate the ability to distinguish light and dark, colors, large gratings and basic physical forms. Conducting acuity tests with the Berkley Rudimentary Vision Charts to establish and define Log Mar vision below the 20/400 line is a good start. At this point, patients with advanced glaucoma, diabetic retinopathy, age related macular degeneration, retinitis pigmentosa, and many others must realize the value of whatever residual vision they have. This will encourage compliance with the control of ocular and systemic diseases leading to blindness.

Patients deal with the sudden traumatic nature of the bad news with denial and disbelief. They view the abyss of isolation and torment socially [5]. Three factors that influence the severity and intensity of shock are: (1) the significance of the loss to the individual, (2) the suddenness or unexpectedness of the event, and (3) the degree of visual loss. Denial often lasts as long as the multiple opinions and therapies continue to change; when the eye care professional admits “we have done all we can do.”

Tedrick [4] reports that self-pity is the main characteristic in the mourning and withdrawal phase. In this phase, individuals refrain from activities that they once loved to partake in. Tuttle and Tuttle [5] outlined the “D’s” of depression as despair, discouragement, disinterest, distress, despondency and dissentment. The next stage in the adjustment process is reassessment and reaffirmation. In this phase/stage the client self-examines their life and finds meaning (purpose for living).

In the next stage (coping and mobilization), the patient will find information and resource that will support them in the change [4]. This phase has cultural overtones that determine how smoothly, and at what rate it progresses. In Jamaica, the go-to is the Society for the Blind and the philanthropic body that supports rehabilitation is the Lions Clubs spread across the island. As the patient crosses this phase into the final of self-acceptance, he/she gains self-confidence, and is able to accept the prognosis and move on with life. This may take a long time, and some may never get there.

4. Faith: influence of beliefs

In societies with strong theosophical backgrounds, the role of religious beliefs and claims to divine intervention are often brought to the fore. Patients facing imminent blindness look to prayer and divine healing in order to stay positive about their prognosis [6]. As a spiritual meditation, the activity has been shown to have physiologic benefits: clinically significant reduction in and ambulatory blood pressure, reduced heart rate, cardiorespiratory

synchronization promotion, altered levels of melatonin and serotonin, suppressed corticostriatal glutamatergic neurotransmission, immune response boosting, decreased levels of reactive oxygen species as measured by ultra-weak photon emission and reduced stress.

Invoking healing through prayer has been compared with the placebo effect, influenced by personality, expectancy, optimism, and motivation. Randomized controlled studies, have been inconclusive about the benefits of prayer, though faith has had documented positive impact on outcomes in treatment groups studied. Considerations given to the Hawthorne and Rosenthal effects have been attributed to some of these outcomes [6]. The Hawthorne effect refers to change that occurs as a result of the act of observation or measurement, whereas the Rosenthal effect refers to change resulting from observer or rater expectancy. Study conditions may foster exaggeration of measurement results on the part of the subject, and relaxation of the measurement criteria on the part of the observer respectively. With specific reference to glaucoma, I have found that patients with a positive attitude maintain functional vision despite advanced disc and Retinal Nerve Fiber Layer (RNFL).

Andrade and Radhakrishnan [6] examined the correlation of medical and psychosocial benefits to religious affiliations and practices by posing a series of questions (see Appendix 7.1). The results were inconclusive and as such a definite relationship could not be determined. The door to research of this nature remains open, with respect to religious and theological customs and beliefs.

Optimism in our patients facing blindness has a positive impact on the way they experience environmental stimuli, and how this information is used in coping strategies optimism may contribute to the well-being of persons who have lost their vision both directly and by promoting problem-focused coping and engagement in positive social comparisons [7]. Research has found that non-acceptance of vision loss, using avoidance or ventilation coping, and not facing reality with a positive outlook may lead to negative feelings and low adaptation. Ophthalmologists' attitudes towards the underlying disease, and how they convey hope or despair to patients, can influence psychosocial adaptation in patients. The concept of neuroplasticity and the individualistic nature of healing and repair cannot be minimized. Shifting the focus to realistic goals such as optimal IOP in glaucoma, and discussing breakthroughs in neuro-therapy such as stem cell research will help keep hope alive and foster positive outlook.

5. The second opinion

Murphy [8] writes of her experience with a poor visual prognosis, where second opinion changed her life in a day, from despair to hope. An ophthalmologist diagnosed her sudden onset of loss of vision as macular hemorrhage of questionable etiology, giving a 2-week period before anticipated total vision loss. Her second opinion from a younger eye surgeon (and has a good prognosis), gave a diagnosis of Central Serous Maculopathy which is self-limiting. Patients are entitled to this review, and doctors should have no insecurities about this, as medical research is very dynamic.

Diagnosis of irreversible (legal) blindness should be made by medical or eye care professionals qualified to make such pronouncements, and the same should be validated by objective methodology as far as is possible. There are legal ramifications to unfavorable visual diagnoses with socio-economic, emotional, vocational, relational, and psychological consequences. Pronouncements should be made in the presence of a legal support system, as well as the full cadre of relevant eye care professionals.

Case in point: Macular holes are common, and when greater than 600 microns, have a poorer prognosis for repair and vision rehabilitation. This, until recently with the advent of autologous blood as an adjunct to macular hole surgery. Research continues to change the prognoses for vision rehabilitation in many cases traditionally considered end-stage. Informed second opinion should be a part of due process in the management of patients with unfavorable visual prognoses that can negatively affect their quality of life [9, 10].

The prognosis of conditions like glaucoma, retinitis pigmentosa and macular degeneration, to name a few are largely subjective. Advice on prognosis and related patient counseling needs to be collaborative, involving psychologist, ophthalmologist, patient, care-givers, and key opinion leaders who can use latest investigative and therapeutic tools to alter the course of progression where possible. Acceptance of a diagnosis and prognosis had a large cultural and socio-economic component that differs significantly according to the cultural milieu [11]. Second opinion in many cases may involve the use of tele-medicine, research, and professional exchanges across borders.

6. Role of sports as a coping mechanism

It is a well-established fact that physical activities including sports, build self-esteem and self-acceptance, as well as enhance physical, mental, and emotional health [12]. This has been known to medicine as far back as B.C. 460 (alluded to by Hippocrates). The International Blind Sports Association (IBSA) is the arm of the Paralympic Movement governing professional and competitive sports for the visually impaired. British athletics in schools was used as an inspiration for developing Paralympic sports, Para (parallel) – lympics (running just after the regular Olympic program) [11]. The running, jumping, and throwing activities were found to boost not only physical wellbeing, but brought inclusion and equality to persons otherwise marginalized due to disabilities. Quoting from the Paralympics manual:

“The fundamental principle guiding the Paralympics movement is that elite level athletes with physical disabilities should have opportunities and experiences equivalent to those afforded elite athletes without disabilities...Competitive sports have proven to be an effective vehicle to promote equality, inclusion, accessibility and awareness about the capabilities of those with physical disability...and dispel the stigma surrounding disability and illuminate the realm of possibility...” [13].

Wanderi [12] looked at the role of sports in the lives of Kenyans in educational institutions and communities on a whole. The Government of Kenya in 1988 outlined a decade plan for the integration of education to the tertiary and post graduate level, where both physically challenged and those desirous of working with the disabled would receive equal training in the universities, a program which spread across academic and sports departments. The 2006–2011

strategic plan of the Ministry of Education in Kenya was a highlight of Kenya Government's commitment to improving the fate of the disabled. Legislations and Governmental policies need to stand behind the inclusion and empowerment of visual impaired in their societies, thus minimizing the sense of dislocation and hopelessness of those with visual, and other physical impairment.

The ability of sports to unite communities, regions, and cultures has been demonstrated time and again, and is even more powerful when viewed from the standpoint of disabilities. There is an added measure of respect and dignity that transcends the winner's podium. Just participation in itself lends to self-confidence, respect from community, and aids the rehabilitative efforts of those caring for the visually impaired. Physical activity among the visually impaired enhances coordination as well as sharpens proprioceptive and other senses that are needed in daily life. There is a bonus in other areas of health that would be threatened by a sedentary lifestyle that can result from the loss of self-confidence and independence accompanying significant vision loss.

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