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Patient expectations of surgery outcomes for appearance-altering eye conditions

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Conditions affecting the eyes can be associated with impaired vision, social functioning and reduced quality of life. Unsurprisingly, patients with these problems often seek surgery to improve their vision and/ or change their appearance. Elizabeth Jenkinson and Sadie Wickwar consider research suggesting that patients may have differing expectations of outcomes that can be achieved with surgical interventions

Appearance-altering conditions affecting any part of the body can present challenges to those affected, in terms of both physical and psychological functioning (Rumsey and Harcourt 2004). Previous articles in this series have highlighted the wide range of psychosocial concerns that can be associated with looking different from others, including anxiety, disrupted social functioning and curtailed intimacy and relationships (e.g. Jenkinson 2014, Sharratt 2015). Whilst this body of research suggests that a visible difference in one particular location of the body is not associated with greater distress than another (Appearance Research Collaboration 2009), the significance of the face, and particularly the eyes, in non-verbal communication is unique. Growing evidence suggests that patients with disfiguring eye conditions could be at particular risk from compromised psychosocial well-being and quality of life (see Clarke et al 2003, Wickwar et al 2015a). This extends to a wide range of conditions including: thyroid eye disease (TED), Strabismus, and Ptosis. Potentially effective surgical interventions are available to many, which may help to improve physical functioning and the appearance of the eyes, and in turn help patients psychosocially. However, not all patients seek surgery and those who do may have differing expectations and motivations for

doing so. Understanding the reasons why patients seek surgery, and what they hope to achieve, is an important area of research to gain a deeper understanding of patient's needs, and satisfaction with their care. This article examines up to date research in this area and suggests how health care professionals may be able to support patients psychologically by understanding their motivations for undergoing a procedure and their expectations regarding outcomes.

Losing sight

Appearance-altering eye conditions can cause a number of debilitating symptoms relating to visual dysfunction. For example, visual difficulties in Strabismus and TED include double vision and TED can also cause partial or complete loss of vision when orbital swelling is severe enough to compress the optic nerve (Terwee et al, 1998). Ptosis, the drooping of one or both eyelids, can obscure vision as the lid can partially cover the eye. These visual impairments can affect all aspects of life including driving, hobbies, and coordination in public places, which lead to loss of independence, increased reliance on others (Estcourt et al, 2008) and often loss of employment (Jackson & Gleeson, 2013; Ponto et al, 2009). Therefore, patients may seek surgery hoping to improve visual acuity to objectively improve their vision with the ultimate aim of facilitating effective social functioning and improving quality of life.

Keeping up appearances

Whilst referrals for surgical intervention on the NHS tend to be based on clinical need in terms of vision or physical measurements, patients themselves may also be highly motivated to seek surgery to change their appearance. This may be due to the noticeable appearance changes in conditions such as TED, Ptosis and Strabismus, where patients frequently cite experiencing the now well

documented negative judgements of others in social situations on the basis of looking different from the norm (see Rumsey and Harcourt 2004, Clarke et al 2003, Richards, Jenkinson, Rumsey and Harrad submitted). However, this is not the case for all. Many patients, even with very noticeable visible differences are able to overcome these challenges with little threat to psychological well-being. Indeed despite prevailing ideology that medical severity will equate to distress, patients' concerns about their appearance are now known to be unrelated to the extent or objective severity of their disfigurement (Rumsey & Harcourt, 2004, Moss 2005, Ong et al 2007). This might explain why, despite quality of life and appearance related anxiety significantly improving after surgery for disfiguring eye conditions, there is often still large variation in outcome (Wickwar et al, 2015b; McBain et al, *submitted*). Research now suggests that this variation may be best explained by focus on patients' individual differences in cognition and psychological processes, rather than clinical measurements. For example, recent research suggests that reducing social anxiety and avoidance, reducing the value and importance placed on appearance, addressing perceptions of noticeability and encouraging positive thoughts about one's own appearance, may help to improve quality of life and/or reduce anxiety over and above clinical factors in a range of appearance-altering eye conditions (James et al 2011, Wickwar et al, 2015b; McBain et al, *submitted*)

Managing expectations

It is clear that many patients may expect not only to experience an improvement in their vision, but also in their appearance, and ultimately quality of life and social interactions, as a result of surgery. Therefore, eliciting and managing patients' expectations throughout the process may help improve patient satisfaction with the care they receive. Research suggests that dissatisfaction with surgical outcomes may be linked to having unrealistically high pre-surgical expectations. For example, patients with TED often report a desire to look exactly how they did prior to their condition only to

find that surgery is unable to achieve this (Estcourt et al, 2008; Wickwar et al, *in preparation*).

Unexpected clinical outcomes affecting appearance such as more scarring than expected can also lead to patient dissatisfaction with ophthalmic treatment (Dawn & Lee, 2004).

Speaking the language of the patient

It could be argued that patients need to be well informed about the possible outcomes of surgery and the information needs of patients with appearance-altering eye conditions are particularly high (Estcourt et al., 2008; Edmunds et al., 2013). Accessing comprehensible information may currently be problematic however. Information online is often aimed at reading levels higher than the average patient (Edmunds et al, 2013), raising concerns for possible misinterpretation. Research also suggests that patients' expectations are informed by the mass media and societal ideals, thus falling well beyond what realistically can be achieved (Clarke, 1998).

One recent study in TED found that patients favour websites that provide "before-and-after" photos of other patients who have had orbital decompression surgery as they are perceived to give a good sense of what to expect from changes in their appearance (Wickwar et al, *under review*). However, if such websites only include examples of ideal case scenarios, this can further raise expectations. This is particularly important in medical consultations offering multiple surgical interventions in an attempt to satisfy patients. It may be that these "conflict with the patient's need to accept a less than perfect outcome" (Rumsey & Harcourt, 2004, p.92).

Media and societal rhetoric regarding eye surgery may also serve as a barrier to electing for surgery. Qualitative research recently conducted by the CAR team suggests that the perceived stigma of having what could be considered by others as 'cosmetic' surgery for Ptosis was a salient concern for both male and female patients (Richards et al submitted). Open discussion with patients may help

to dispel myths about outcomes exacerbated by media and internet sources, allay concerns, and ensure patients make informed decisions about their care.

Providing psychosocial support alongside surgery

Research also suggests that psychosocial support as an adjunct to surgery may be well received by patients. Whilst patients are routinely offered support after the loss of an eye, patients with TED are not commonly offered support following their diagnosis (Clarke et al., 2003). Only 27% of patients with TED in the UK feel that they've been helped to deal with the psychosocial impact of their condition (Estcourt et al., 2009) and there is a glaring lack of support for those with eye conditions considered less severe, such as Ptosis (Richards et al, submitted). Considering that some of the highest levels of appearance-related distress and social avoidance are seen amongst patients with appearance-altering eye conditions (Clarke et al., 2003; Richards et al., 2014), it is likely that patients would benefit from psychological support designed specifically to target the issues important to them. As identified by TED patients themselves at a recent Patient and Public Involvement event, responding to these psychological patient needs is a key priority for future research and practice (Smith et al., 2014).

Conclusion

Patients may be driven to seek surgery to alleviate the visual, appearance-related, and psychosocial consequences of their eye condition and as such may have varied expectations for what surgery can achieve. Health Care Professionals have an opportunity to help patients make informed choices and to support them through the process. Research to further our understanding of the psychological

needs of this often overlooked patient group is required and the development of guidelines for delivering effective patient support is a focus for the future.

Key words: eye conditions, expectations, surgery, psychology

Key points

- 1) Research suggests that appearance altering eye conditions such as Thyroid Eye Disease, Strabismus and Ptosis may have negative psychosocial impacts for patients in addition to impacts on vision.
- 2) Therefore, where surgery is offered, patients' expectations of surgical outcomes may extend beyond improving visual functioning, to improving or even restoring appearance, and improving quality of life.
- 3) However, research suggests that these often high expectations may result in patient dissatisfaction if outcomes are not met.
- 4) Health care professionals can help manage expectations by providing reliable and accessible information on clinical outcomes and by helping support patients experiencing the psychosocial challenges associated with appearance altering eye conditions.

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