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Citation: Wickwar, S. (2015). What is the psychological impact of thyroid eye disease and does orbital decompression surgery improve outcomes?. TEDct Newsletter (Associated with The British Thyroid Foundation)(Spring),

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What is the psychological impact of thyroid eye disease – and does orbital decompression surgery improve outcomes?

Over the years research on thyroid eye disease (TED) has focused on what causes the disease and how to treat it effectively. Less research has focused on the psychological impact of having TED. There has been growing interest in how TED affects overall quality of life in recent years however and Caroline Terwee and colleagues in The Netherlands developed a useful questionnaire to help this area of research develop. By asking people with TED to help design the questionnaire – the Graves' Ophthalmology Quality of Life Questionnaire (or GO-QOL) – it captures issues central to TED, including feeling stared at in the street by others, having difficulty reading, and avoiding appearing in photographs¹. The authors urged researchers to use the questionnaire in every trial that investigates a new treatment for TED, to assess whether treatments improve these important aspects of peoples' lives and not just clinical criteria².

Research following this has consistently found TED to have a significant impact on daily activities including reading, watching TV, and driving³⁻⁵, but often for the impact of a changed appearance to be substantially greater³⁻⁵. However, not everyone with TED is affected by the change in their appearance or problems with their vision to the same extent.

Traditionally, the medical assumption has been that the more severe a disease, the worse it will affect a person psychologically. But more and more research has found this not to be the case, particularly when a disease affects a person's physical appearance. Eyes are central in communication and evidence suggests that a change in the appearance of the eyes can be particularly distressing⁶, even when considered to be 'mildly' or 'moderately' severe according to clinical measurements⁷. Our research aimed to investigate the differences in people's adjustment to having TED.

This involved recruiting adults with TED being listed for orbital decompression surgery at Moorfields Eye Hospital (MEH), London, and Birmingham and Midland Eye Centre (BMEC). One hundred and twenty one people kindly filled in a series of questionnaires that asked about their thoughts and experiences, before and after orbital decompression surgery. Orbital decompression surgery – which involves the removal of some of the bony wall around the eyes – aims to reduce proptosis, relieve unpleasant symptoms, and save sight in cases where the optic nerve has been compressed. Fourteen people with TED also took part in interviews with the author before their surgery.

We found that as many as 37% of people with TED are highly anxious and around a quarter feel depressed prior to their surgery, these numbers being greater than the general population⁸ and those living with other conditions causing visible changes to the face⁹.

Having strabismus, ptosis, ocular cancer and trauma have all been found to significantly increase a fear of being judged negatively by others¹⁰ and this study found that this is also the case for people with TED. TED also appears to increase the tendency to compare yourself to other people you know.

Concern about appearance is relatively high in the general population, particularly for women¹¹. This isn't surprising given that we live in a society obsessed with beauty and 'perfection'. Images in the media often unhelpfully portray unrealistic ideals that people less satisfied with their own appearance might strive for¹². Sadly, this can lead to withdrawal from social situations for those

particularly affected. It seems this is a particular issue in TED, where our study found far higher levels of appearance concern than the general population, with no difference between men and women. It seems that a change in appearance to the eyes leads to a tendency to be distressed by your own appearance in people who may not have been normally. Fortunately, levels and quality of social support were particularly high in our study, suggesting that many feel they are being supported by their friends and family through the challenges of TED.

Using the GO-QOL, our study found that appearance-related quality of life was particularly low, although there were large differences between people. Suggesting that for some, the impact of having a changed appearance is extreme whilst others are able to adjust more positively. So what could explain this difference? Our study suggests that being female, being more distressed about your appearance, appearance being central in everyday thoughts, negatively evaluating your own appearance and feeling depressed were associated with adjusting poorly to changes in appearance caused by TED. Not everyone in our study experienced double vision or optic nerve compression – but being older, having TED more severely in one eye over the other, and feeling depressed, were associated with having more problems with day to day vision-related activities¹³.

Our interview study captured in-depth accounts of living with TED and people's expectations of their upcoming surgery. Overall, many perceived surgery to be inevitable, and the gateway to restoring their appearance and enabling them to get back to the life they had before TED. Feelings of anxiety and frustration in the period leading up to surgery were common. Many lacked clarity over exactly what to expect of orbital decompression, and of their appearance after surgery, remaining tentative and hopeful for a "best case" scenario. Good quality, reliable information was often not available online and existing information was found to be confusing and misleading. A number of people found they couldn't process all the information they were given by healthcare professionals in one appointment. Participants reported wanting further explanation from healthcare professionals in future appointments about information they had found online.

Our findings after surgery were that it wasn't easy to predict who would benefit most from surgery from the clinical and psychological factors people presented for surgery with. This highlights the importance for surgeons not to assume who will feel better psychologically after surgery from how severe their TED is (in terms of their proptosis and other symptoms), or from their thoughts about their appearance, prior to surgery. We did however find that orbital decompression was able to improve appearance-related thoughts, and the severity of TED, for most. The reductions in fearing others' judgements and distress about appearance, and improvements in mood and personal evaluation of appearance, all influenced improvements in overall quality of life after surgery.

The findings of this study suggest that it is possible to improve overall quality of life after surgery even more through support interventions that aim to help people improve the way they think about their appearance. The findings of the study could also help to inform shared decision making between surgeons and their patients in future consultations. Sadie and her research team hope to continue this line of research once further funding has been secured.

Acknowledgements

I wish to thank all our research participants from Moorfields Eye Hospital (MEH) and Birmingham and Midland Eye Centre (BMEC). I know the questionnaires were long and time consuming so I'm

extremely grateful for everybody's input. Many people took the time to talk to me during their clinic visits at MEH and in interviews at BMEC, which helped me get a true insight into what it is like to live with TED. I would like to assure everyone who took part in this research that all data was anonymised and their names will not be published anywhere.

I'd also like to thank my colleagues at MEH and BMEC for their expertise and for helping the studies run so smoothly and my co-authors in supervising and guiding this research. Finally, without funding from City University London and the Special Trustees at Moorfields Eye Hospital, this research would not have been possible.

About the author

Dr Sadie Wickwar is a Trainee Health Psychologist and Research Fellow at City University London. She recently completed her PhD research on the psychosocial outcomes of orbital decompression surgery for TED and has presented at conferences across the UK to both clinical and health psychology audiences with plans to present internationally this year. You can contact Sadie via email on sadie.wickwar.1@city.ac.uk if you would like further information about this research project.

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