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**Patients' Expectations for the Functional and Psychosocial Outcomes of Orbital
Decompression Surgery for Thyroid Eye Disease: A Qualitative Study**

Psychology, Health & Medicine

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Abstract

Patients with appearance-altering conditions may be dissatisfied with the outcomes of reconstructive surgery due to unmet expectations. This study explored patients' expectations of orbital decompression surgery for thyroid eye disease (TED) and whether these were met.

Semi-structured interviews were conducted at two times: (1) in the weeks after patients were listed for decompression surgery and before surgery; (2) up to 12 months after surgery.

Thematic analysis was performed for each time point, to identify themes within the data.

Fourteen adults with TED were interviewed prior to surgery and five were followed up after surgery.

Thematic analyses found: (1) Prior to surgery, patients had formed expectations through online information about the procedure, consultations with physicians, the impact TED had on their lives, and speaking to relevant others. Patients had specific expectations about the procedure, the recovery, post-operative appearance and post-operative vision. (2) After surgery, patients generally felt their appearance and well-being had improved. However, dissatisfaction was linked to unanticipated specific aspects of surgical care, recovery, or appearance.

Dissatisfaction can arise from unmet expectations for the outcomes of reconstructive surgery.

Physicians should be aware of the processes by which patients form expectations, for example different types and quality of online information. Ensuring that preoperative expectations are realistic could enhance satisfaction after surgery.

Keywords: Thyroid eye disease, Reconstructive surgery, Patient expectations, Psychosocial adjustment, Treatment satisfaction

Thyroid eye disease (TED) is an autoimmune disease causing inflammation, redness, and swelling of the muscles around the eyes, this pushing the eyes forward (proptosis). TED can cause double vision, loss of vision occurs in up to 10% (Cawood, Moriarty & O'Shea, 2004; Perros et al., 1993), poor quality of life (Terwee et al., 2002; Wickwar et al., 2015) and social withdrawal (Jensen & Harder, 2011; Wickwar et al., 2015). Orbital decompression surgery, involving removal of the bony wall(s) of the eye sockets to make space for swollen muscles, is associated with improvements in quality of life (EUGOGO, 2009; Wickwar et al., 2014). However, despite experiencing clinically meaningful improvement in appearance and/or vision, a proportion of patients are dissatisfied with surgical outcomes (Tehrani et al., 2004). Research suggests that unrealistic expectations may lead to dissatisfaction after eye surgery (Dawn & Lee, 2004; Pager, 2004) and across a wide range of other surgeries (Klassen, Pusic, Scott, Klok & Cano, 2009; Bramwell, Morland & Garden, 2007; Haas 1999). What an individual with TED expects from their treatment may therefore predict psychological adjustment after surgery. Estcourt and colleagues (2008) report that some patients have unrealistic expectations that surgery will enable them to return to the life they had before TED, which may predict psychological adjustment after decompression surgery but has not yet been explored.

Methods

This study employed a longitudinal qualitative design, with interviews before and after surgery. Ethical approval for this study was obtained from the North London Research Ethics Committee (REC reference 11/H0724/6).

Consecutive adults with a consultant-led diagnosis of TED who were identified as eligible for surgery were invited to participate, between October 2012 and February 2014 from an outpatient eye clinic in the UK. Patients were excluded if they had inadequate comprehension of written and spoken English, or were suffering from co-morbid health conditions that rendered them too ill or distressed to take part.

In-depth semi-structured interviews were conducted by a Trainee Health Psychologist experienced in using qualitative methods. An interview topic guide was developed (Figure 1) and guided by previous research on patient expectations of reconstructive or appearance-altering surgery (Klassen et al., 2009; Haas, 1999; Bramwell, Morland & Garden, 2007). All interviews were held either in the research department of the treating hospital, or at the participant's home.

Sample size

To ensure data saturation (Francis et al. 2010) a sample size of between 12 and 15 would be recruited.

Analysis

Thematic analysis was employed to analyse first the pre- and then the post-operative interviews, this involved searching the dataset to identify, analyse and report patterns within the data (Braun & Clarke, 2006). The Consolidated Criteria for Reporting Qualitative Research (COREQ; Tong, Sainsbury & Craig, 2007) was used to ensure transparency of

reporting. A health psychology researcher coded 20% of the interviews to ensure accuracy of the coding process and any discrepancies were discussed by the two researchers until consensus was reached.

Results

Twenty-two patients were identified as eligible and 3 could not be contacted by telephone despite multiple attempts. Of the 19 contacted, 5 were unable to attend an interview before surgery. Fourteen patients gave written consent and were interviewed before surgery.

Demographic characteristics are shown in Table 1.

[Insert Table 1 Here]

Five of the original 14 participants underwent surgery and were available to take part in a follow-up interview post-surgery (Table 2). The average time between pre- and post-operative interviews was 8.5 months. Reasons for not taking part in a second interview included being too unwell (1 patient), surgery being cancelled (4 patients), and not responding to invitations to participate (4 patients). Interviews lasted between 16 and 101 minutes.

[Insert Table 2 Here]

Pre-operative interviews

Two overarching processes were identified before surgery, and seven themes were identified within these (Table 3).

[Insert Table 3 Here]

Most participants described **perceived risks** associated with orbital decompression which reflected information given to them by their surgical team, such as blindness, and many participants balanced the expected benefits of surgery against these perceived risks, and felt

surgery was worthwhile. **Confidence in the surgical team** was an important factor in determining patients' perceived likelihood of surgical complications and their anxiety about the surgery. For most, **recovery time** was an important issue, with concerns about employment and potential side effects. The **timing of surgery** was an issue for many participants, there was definite frustration about the length of the waiting-list; delays in the surgery occurring were found to be extremely distressing, as surgery was viewed as the next step towards returning to "*normal life*".

Many participants struggled to articulate exactly what they expected in terms of their **post-operative appearance**, tending to use general terms such as "*normal*" or "*better*". This inability to fully imagine their appearance after surgery was worrying for some, and was often attributed to a lack of information.

Before surgery, participants described negative comments and feeling "*stared at*" when going out in public, and three participants no longer attending family occasions because of a fear of being amongst others. Participants felt an improved appearance after surgery would have an impact on their confidence during **social interactions**.

The underlying narrative was their understanding that there would not be an immediate improvement, and that **rehabilitation** often involved further surgery. Participants held varied beliefs about the ability of surgery to resolve **function**, including vision, and some spoke about their hopes for double vision to be resolved.

All participants talked about what had **influenced** their expectations, including the **consequences of living with TED**, such as being unable to work and withdrawal from social occasions. This impact motivated them to have surgery and influenced positive expectations that life in general would improve.

A number of participants described how **others had influenced their decision** to have surgery. In one example a decision was made to seek further advice from the surgeon before committing to surgery, as a family member was concerned about the risks. Other participants had met patients who had already undergone surgery and were influenced by their positive experiences. Participants had mixed experiences of how surgery was presented to them by their surgical team: some felt they were expected to have surgery and others felt free to make their own choice. Some attributed their **lack of understanding** about what surgery would involve to the difficulty in recalling information from pre-operative consultations.

Participants described the various **sources of information** they used to find out more about orbital decompression, including websites, blogs and forums. Videos of the procedure and ‘before-and-after’ photos of other patients were commonly found online, with mixed reactions. Some found graphic information reassuring, while others actively avoided it as they found it too distressing.

Post-operative interviews

Six themes were identified within the post-operative interviews (Table 4).

[Insert Table 4 Here]

Participants felt the **information they received prior to surgery** had prepared them for the worst possible outcome, which was not always experienced. Participants were generally satisfied with the information they had been given about *recovery*, although some participants felt that information from healthcare professionals lacked the detail to enable them to form realistic expectations about their *appearance*; participants felt that their expectations had not been explored by their surgeon prior to surgery. Some participants felt videos and other online information helped them form more realistic expectations.

All participants reflected on their experiences of surgery and the unexpected aspects of **surgical care**. Participants were generally satisfied with the care they had received, although unexpected problems, such as surgery being postponed, were particularly distressing. After **the recovery process** participants described feeling less concerned about the expected side effects, for example bruising, and reflected on wanting more information before surgery about the unexpected side effects, such as facial numbness.

Overall, participants **perceived improvements in their post-operative appearance**, although there were mixed feelings about whether these outcomes had met expectations. After surgery, some expressed a desire to improve appearance further through additional surgical procedures (particularly patients who were **dissatisfied with their post-operative appearance**), whilst others preferred not to “*gamble*” with their appearance. Participants reported feeling more confident during **social interactions** since having surgery along with improvements in their well-being. Some participants described feeling a sense of freedom, reflecting a return to “normality”.

Some participants had **functional** difficulties after surgery, such as blurred vision, but expected these to resolve over time, and some were disappointed with persistent double vision after surgery.

Discussion

This was the first study to examine in depth the expectations patients with TED have about orbital decompression surgery, what influences these expectations, and whether expectations were met post-surgery. One important theme to emerge from this study was the high information needs of patients, and how this was related to communication with healthcare professionals. Participants often struggled to recall or articulate exactly what they had been told prior to surgery, which may reflect the emotional nature of consultations in which surgical interventions are offered (Harcourt & Rumsey, 2001). Coupled with excessive use of medical jargon and technical terms (Newell, Ziegler, Stafford & Lewin, 2004), it is unsurprising that patients undergoing surgery may not understand all of the information given to them. There is evidence that when specific patient-centred communication skills, such as empathy (Rodin et al., 2009), are used in medical consultations this can increase patients satisfaction. This would be worth further exploration in the context of surgery for appearance-altering eye conditions.

Many patients looked for online information to feel more informed about orbital decompression, a potential danger given the uncontrolled nature of the internet. Whilst surgical videos have been found to increase perceived knowledge, they do not always increase factual knowledge (Zvara, Mathes, Brooker & McKinley, 1996), making way for potentially unrealistic expectations. Furthermore, TED-specific websites have been found to be aimed at reading levels higher than that of the general population (Edmunds et al., 2013), this increasing the chances of misinterpreting online information, highlighting the importance of healthcare professionals in providing information about all potential outcomes of surgery, along with exploring and challenging any unrealistic expectations. Valid and reliable tools have been developed in recent years to support clinicians in eliciting expectations in the

context of eye treatment, such as the Eye Care Expectations Survey (Dawn, McGwin & Lee, 2005).

Patients placed their trust in their surgical team, contradicting previous research in TED that reports difficulties in developing confidence in healthcare professionals (Estcourt, Quinn & Vaidya, 2011; Estcourt et al., 2008). After surgery, however, there were mixed reactions to surgical care, sometimes due to technical issues meaning surgery had to be postponed. As previously found for other disfiguring conditions, unrealistic expectations about the impact of surgery on their appearance, including expecting to return to a pre-morbid appearance, were found to lead to dissatisfaction after surgery (Partridge, 2006; Kiyak, Vitaliano & Crinean, 1988; Finlay, Atkinson & Moos, 1995).

This is the first study to investigate the post-surgical expectations of patients with TED. It is however limited by the one geographical location in the UK and the small sample size post-surgery, reducing the general applicability of the findings in relation to whether expectations after decompression surgery are met. We recommend future research to further explore this in a larger sample of participants and establish the psychological impact of unmet expectations.

Conclusions

Patients with TED have high, and in some cases unrealistic, pre-operative expectations of their surgical care, recovery, appearance and visual functioning post decompression surgery. This study highlights the importance of healthcare professionals eliciting and managing patients' expectations, in order to optimise surgical outcomes.

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Figure 1. The interview topic guide used for the pre-operative interviews

Topics: *current impact of illness on daily activities; current feelings about appearance; treatment options; personal reasons for having surgery; goals for surgery/ outcomes; motivation for going forward with surgery; any influences that others have had on their decision to go for surgery; any events related to appearance that might have had an impact on decision to have surgery; what preparations might they have made for surgery; what are they expecting about outcomes*

Introduction

- 1) Can you tell me about the impact TED might have had on your daily life?
Prompt: Can you tell me about the impact TED might have had on your appearance?
Prompt: Can you tell me about the impact that TED might have had on how you feel about yourself?

Motivation(s) for having surgery

- 2) When did you first start thinking about having surgery?
- 3) Did you consider alternative treatment options? If so, reasons for choosing surgery over others?
- 4) What do you feel your reasons might be for having surgery?
- 5) Could you tell me what is motivating you to have this surgery?
- 6) Are there any particular goals you hope to achieve by having surgery?
- 7) Can you tell me if anything has influenced your decision to have surgery?
- 8) Could you tell me about what you might have done to prepare for your surgery, or that you plan on doing to prepare before your surgery?

Information about surgery

- 9) Can you tell me about the information you have been given about your surgery?
Prompt: By your doctor/ surgeon, nurses, any other healthcare professional?
- 10) Can you tell me if you have tried to find out more about orbital decompression surgery? If so, where did you look?
- 11) What do you feel about the information you have been given, or that you have found, about your surgery?
- 12) Can you describe what you expect from the surgery based on the information you have been given, or that you have found?
Prompt: On the day of surgery, leaving hospital, recovery?

Expectations of surgery

- 13) Can you tell me what outcomes you might be expecting from your surgery?
Prompt: Appearance outcomes? Daily life outcomes?

Table 1. Characteristics of participants prior to surgery

Variable	n (%)	Range	Mean
Age (years)		23 – 76	47.2
Gender			
	<i>Male</i>	4 (28.6)	
	<i>Female</i>	10 (71.4)	
Ethnicity			
	<i>White British</i>	10 (71.4)	
	<i>Asian</i>	2 (14.3)	
	<i>Black African/Caribbean/Other</i>	2 (14.3)	
Employment			
	<i>Full time employed</i>	7 (50)	
	<i>Retired</i>	3 (21.4)	
	<i>Unemployed</i>	4 (28.6)	
Relationship Status			
	<i>Married/Living with partner</i>	10 (71.4)	
	<i>Single/Other</i>	4 (28.6)	
Disease duration (months)		10 - 480	64.7
Laterality of GO			
	<i>Bilateral</i>	13 (92.9)	
	<i>Unilateral</i>	1 (7.1)	
Treatment history			
	<i>Previous steroid medication</i>	8 (57)	
	<i>Previous radiotherapy</i>	4 (28.6)	
	<i>Previous eyelid or orbital surgery</i>	3 (21.4)	
Optic neuropathy		0 (0)	
Diplopia		8 (57)	

Table 2. Participants interviewed pre- and/or post-surgery

Study Number	Gender	Laterality of Surgery	Interviewed post-surgery
01	F	Bilateral	Yes
02	M	Bilateral	No
03	M	Unilateral	No
04	F	Unilateral	Yes
05	M	Unilateral	Yes
06	F	Unilateral	No
07	F	Bilateral	Yes
08	F	Bilateral	No
09	M	Bilateral	No
10	F	Bilateral	No
11	F	Unilateral	Yes
12	F	Unilateral	No
13	F	Bilateral	No
14	F	Unilateral	No

‡Radioiodine therapy, RAI; oral steroids, OS; intravenous steroids, IS; radiotherapy, RT; orbital decompression on one eye, OD

Table 3. The final themes and sub-themes identified using thematic analysis for the pre-operative interviews

Overarching Process: Expectations of orbital decompression surgery		
Theme	Sub-theme	Sample Quotes
The surgical process	<i>Risk perception</i>	“I just want to move forward, and if that means taking a risk with one of my eyes, and I’m pretty sure that they wouldn’t recommend it if they didn’t have such a good success rate, and I think that’s a massive thing” – 10
		“I know there are risks with the operation. And to me, the risks if I don’t have it done are definite...If I have the op done it’s, yes there can be complications, but it’s not certain that you’ll get them.” – 11
	<i>Confidence in surgeons and healthcare system</i>	“There are varying degrees of things that could go wrong or in the worst case I could lose an eye, but I’m in [the surgeon’s] hands” – 03
		“I have every confidence in [the surgeon]...otherwise I would never have agreed to it, never in a million years I wouldn’t. It’s too precious, isn’t it? It’s your eyes” – 10
Recovery	<i>Timing of surgery</i>	“It was my starting point to getting things sorted, because if they do that one they’ve got to do the second one and then I can try and get my life back on track” – 07
		“I rang the hospital last week, because I need to get it done, move on, get it out the way...and it was constantly engaged and I was getting really frustrated...I just want a date now.” – 10
		“One of the first questions I asked [the surgeon] was how long am I going to be off work? Because the summer time is my busy time” – 02
		“I was more concerned I think when they said it was bilateral rather than unilateral, I thought ‘oh...that’s a bigger op then’. And then of course after that you think oh, well what’s going to be the healing time on that? How long will I be out of action?”- 11
	<i>Ill-formed expectations</i>	“The only thing I was expecting was the prominence will be less, but I

Post-operative appearance		don't know to what extent. Will I look exactly like [I looked] before?" – 06
	<i>Social interaction</i>	"Hopefully the redness will go. And they will just go back to a more normal position" – 07
	<i>Rehabilitation timeline</i>	"Hopefully I can hold my head up, look at someone in the eye and have a conversation with them, rather than look at the floor or look at the table" – 07
		"I'm hoping soon I will start going out with my friends again"- 12
		"I don't expect it to happen overnight, I know it's going to be a long process"- 01
		"I know it's not a quick fix. I know that, and I've always said I know it's not a quick fix. And I know that it's going to take time" – 07
Post-operative function		"I'm hoping that it is going to help with the vision as well, though I do understand that there may be other surgery afterwards that may be needed to help with the vision" – 01
		"I was quite looking forward to having this done... so that I haven't got double vision"- 03
Overarching Process: Forming expectations		
Theme	Sub-theme	Sample Quotes
Consequences of living with TED		"We had no choice, we tried everything. Different medications, radiotherapy, that didn't work. Everything was just taking it so far and not curing it, surgery was the last resort" – 09
		"The big thing for me is obviously when you're getting married, being the bride everybody's looking at you" – 14
Influence of others		"[My brother] thinks that I shouldn't have the operation. He thinks that the prominence is not very big and because of the risk I shouldn't have it" – 06
		"I'd say a big influence really has been from what [my friend] said about

	[the surgeon] ...the outcome, she said, it's been fantastic" – 13
<i>Sources of information</i>	"Don't type it into <i>YouTube</i> and look at it because it's horrible" – 05
Impact of information	"In some ways it helps because you see it and you know exactly what you're in for... I think the more you understand about something the more informed you are, the more you can anticipate and expect what's going to happen" – 01
<i>Degree of understanding</i>	"Probably 50% of people don't fully listen to what a doctor's telling you because you're trying to digest the first part. OK, if you don't do this, you're going to have no eyesight. My brain's trying to sort that out, and they're trying to explain to you everything else." – 10

Table 4. The final themes and sub-themes identified using thematic analysis for the post-operative interviews

Theme	Sub-theme	Sample Quotes
Pre-operative information		“What if this goes wrong? What if the drill slips? You could be paralysed, you could lose your sight...I did have a few second thoughts” – 04
		“They don’t dwell too much on the expectations but you are sort of told that visually it’s going to look better and ... you think it’s going to make a big difference.” – 01
Experience of surgical care		“They were a bit disorganised first thing in the morning... nobody seems to know quite what’s going on.” – 04
		“You are so deflated, because you think ‘here we go again’. It’s just a waiting game all the time. I think they can keep you more informed.” – 07
Experience of recovery		“My immediate feelings were ‘I’ve done three rounds with Mike Tyson!’ The bruising was really quite horrendous but I mean, I was expecting it and I do bruise easily so...it was no worse than one expected.” – 04
		“It took quite a while before you could open your mouth to actually take a bite of something ...as long as you knew it would get better it was fine, I just thought perhaps they should warn people about that.” – 11
Reactions to post-operative appearance	<i>Improvements in appearance</i>	“I was really pleased, I didn’t think it would work as well as it did... but I was really quite surprised when all the swelling went down, how far back it had gone and how almost <i>normal</i> it looked.” – 11
	<i>Dissatisfactions with appearance</i>	“Without being picky it really isn’t balanced...I would consider if there was something else to be done... I do still feel there’s room for improvement.” – 01
Post-operative function		“I get slightly blurry vision first thing in the morning if I look up too fast, but that’s just, it’s just getting used to what has been done, it takes ages for things to recover correctly” – 05
Psychosocial well-	<i>Social reintegration</i>	“I didn’t go anywhere, in fact I think the last time I went into town, which isn’t a great distance, was four years ago, but now I’m quite happy to go...

being	I just feel a lot more confident with people and facing them instead of hiding behind a door” – 07
<i>Psychological well-being</i>	“I’ve got a sense of, I don’t know, a sense of since I’ve not got anything holding me back, I can do anything I want.” – 05
