1	'Pre-Operative Experiences and Post-Operative Benefits of Ptosis Surgery: A
2	Qualitative Study.'
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19 Abstract

20 This gualitative study sought to explore the experiences of patients who had 21 undergone successful ptosis correction surgery. Participants were recruited from 22 Bristol Eye Hospital. Nine participants were interviewed using a semi-structured 23 interview schedule and open ended questions. Data were analysed using Inductive 24 Thematic Analysis. Four major themes were identified from patient accounts. 25 Patients described the psychosocial and functional difficulties they experienced living 26 with ptosis, and the subsequent benefits of surgery. Patients reported experiencing 27 appearance related anxiety pre-operatively due to their condition and engaging in 28 behaviours to avoid social encounters. Gender differences were noted in the 29 internalization of perceived negative reactions from others, with men describing 30 fewer adverse impacts. Patients described perceived barriers to seeking surgery 31 including a lack of awareness of ptosis as a treatable condition, the perception that 32 being concerned with their appearance could be seen as vain and the view that 33 ptosis surgery is synonymous with cosmetic surgery. Following successful surgery 34 patients outlined positive impacts on their vision, appearance and psychosocial well-35 being after successful surgery. This qualitative study highlights the complexities of 36 the factors and processes contributing to the psychosocial impacts of ptosis and the 37 potential benefits of surgery and/or psychosocial support. An increased awareness 38 amongst people with ptosis of the potential positive impacts of surgery and an 39 enhanced understanding of the reasons why patients may not seek treatment 40 amongst health care professionals are likely to benefit this often overlooked patient 41 group.

42

43 Introduction

44 Ptosis is a condition which involves the drooping of one or both eyelids. This can 45 have negative impacts on vision and facial appearance. Ptosis correction is generally 46 a straightforward and successful oculoplastic procedure. However, there is well 47 documented stigma associated with treatments perceived to be 'cosmetic'. Western 48 media portrays plastic surgery procedures as primarily 'aesthetic' and under-49 represents the complexities involved in undertaking reconstructive surgery(1). 50 Research also suggests that journalists tend to perceive plastic surgery as being 51 synonymous with cosmetic surgery(2), with the terms 'aesthetic', 'cosmetic' and 52 'plastic surgery' being used interchangeably(3).

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54 These misconceptions may also extend to medical professionals. Clarke(4) 55 highlighted a general misperception within the NHS concerning plastic surgery and 56 cosmetic procedures. GPs and medical students perceived plastic surgery to be 57 associated with the treatment of aesthetic conditions to a greater extent than 58 reconstructive procedures such as hand surgery(5). This finding is concerning, as 59 general practice is often the route for patients to access reconstructive treatments(6). 60 (7). In addition, access to corrective plastic surgery procedures varies between 61 Trusts. Within oculoplastics, there are widespread inconsistencies across NHS 62 Clinical Commissioning Groups (CCGs) in relation to the purpose of surgery for 63 ptosis, and the criterion by which treatment is commissioned. Some CCGs perceive ptosis surgery as an aesthetic procedure and will not commission it under any 64 65 circumstances(8). Others state they will not commission ptosis surgery for cosmetic 66 reasons, but will do so where there is objective evidence of impairment to visual fields(9) (10) (11), with some using specific eligibility criteria for treatment, for 67 68 example, the upper margin reflex distance and degree of eyelid asymmetry(12).

69 Previous research into the impact of ptosis and other conditions affecting the 70 appearance of the eyes(13) (14) (15) demonstrates negative impacts of these 71 conditions due to the psychosocial effects of living with an appearance altering 72 condition, and suggests that patients with ptosis may be motivated to seek surgery to 73 ameliorate the psychological impacts as well the functional concomitants of the 74 condition(15) (13). The withholding of ptosis surgery on the grounds that it is a 75 cosmetic procedure and is therefore unworthy of funding risks denying treatment to 76 patients experiencing significant reductions in guality of life (QOL) as the result of the 77 condition. Differences in commissioning practices and the likelihood that surgical 78 intervention is being withheld from those who may benefit, highlight the need for an 79 in-depth exploration of the psychological and social impacts of ptosis and the extent 80 to which surgery can have psychological benefits.

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82 This study sought to explore patients experiences in their own words as those who 83 have undergone ptosis surgery are ideally placed to provide data on the benefits or 84 otherwise of treatment, the impacts of ptosis on psychosocial functioning prior to 85 treatment and the motivations for seeking treatment. The success of ptosis surgery 86 is generally assessed by surgeons using objective measures of outcome including 87 cosmesis(16) (17) (18). Subjective patient reported outcomes are rarely reported 88 with the majority of existing outcome studies focusing on functional improvements 89 and changes to guality of life as the result of enhancing visual functioning (19) (20). 90 Although one study has examined the psychosocial impact of ptosis using open 91 ended questions to explore patient accounts in their own words to gain greater 92 understanding of the needs of affected groups(21), this study focused on ptosis as a 93 symptom of Myasthenia Gravis. Further insight into patient reported motivations for

94 treatment and outcomes is necessary to inform efforts to improve understanding of 95 ptosis and the potential benefits of treatment. . Qualitative methods offer the best 96 means of providing in depth data from the patient perspective (22) and findings from 97 person-centered methodologies are recognised as key, in conjunction with 98 subsequent broader scale quantitative work, in informing patient care. (23). 99 100 This study aims to address the current gap in understanding by gathering qualitative 101 interview data to explore patients' motivations for seeking treatment, the impact of 102 ptosis surgery in terms of changes from pre-operative state and factors contributing 103 to individual differences in these processes, in order to improve current 104 understanding of patients' experiences of ptosis surgery and to inform 105 commissioning and provision of care. 106 **Materials and Method** 107 108 109 Design 110 111 Semi-structured interviews were conducted as this format offers the flexibility 112 necessary to explore the individual perspectives, whilst maintaining the focus of data 113 collection in relation to the aims of the study. Topics were developed following an 114 earlier online study(13), in which people with ptosis were consulted about the 115 development of this and related studies. Questions included "How did your ptosis 116 affect you day-to-day? Has this changed since your surgery?' In line with sampling guidance from Braun & Clarke(24) interviews were conducted until no new concepts 117 118 were identified. This approach ensures a broad range of data is collected and is

widely used in health science research(25). Due to the labour intensive and in-depth
nature of qualitative research and the amount of data generated by each participant,
smaller sample sizes are used compared to quantitative studies, with a sample size
between 6 and 14 considered appropriate for inductive qualitative research of people
with a specific health condition(26), (25) (24).

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125 Participants

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127 Adult patients were recruited from the Bristol Eye Hospital. Participants were eligible 128 to participate if they were over 18, had unilateral or bilateral ptosis and were fluent in 129 English. Patients were approached post-operatively, and interviews were conducted 130 in the clinic setting, immediately following their final post-operative appointment. Nine 131 patients were interviewed. Four participants were female, ages ranged from 24-75 132 years old (mean=63). Five patients had unilateral ptosis, four had bilateral ptosis. For 133 eight patients surgery was undertaken primarily to improve vision. One patient had 134 surgery because of discomfort due to ptosis. All patients underwent levator 135 aponeurosis repair or advancement procedures. Two patients required a repeat 136 procedure due to poor initial results. All patients' results were described as 'very good', 'symmetrical' or 'with no further surgery needed' at discharge. 137 138 139 Data analysis

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141 Interviews were recorded and transcribed verbatim. Inductive Thematic Analysis was
142 used to analyse the data in accordance with six-step guidelines described by Braun
143 & Clarke(27). Transcribed interviews were read and re-read to ensure in-depth

- 144 familiarity with the data, allowing patterns in the data to be observed and coded.
- 145 Codes were then grouped together into themes and associated sub-themes and
- 146 verified by two researchers to ensure accuracy.
- 147

148 Ethical statement

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- 150 Ethical approval was obtained from the host NHS Trust and University
- 151 Research Ethics Committee. All participants volunteered to take part after
- 152 giving full informed consent and were reminded of their right to withdraw at
- any point, and the arrangements for confidentiality of the data obtained.
- 154 Pseudonyms have been used to protect participant identity. All investigations
- 155 were conducted in accordance with the Declarations of Helsinki.
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157 **Results**

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Four themes were identified; Appearance Related Anxiety & Behaviours, Lack of
Awareness of Ptosis as a Treatable Condition, Appearance Concern as Vanity and
the Stigma of Cosmetic Surgery and Seeing Better and Feeling Better. The themes
and sub-themes are outlined below.

163

164 Theme 1: Appearance Related Anxieties and Avoidant Behaviours: "All they

- 165 are going to see is the eye":
- 166

167 Patients discussed the psychosocial impact of ptosis prior to treatment, reporting 168 negative impacts on self-esteem and self-confidence, increases in levels of self-169 consciousness, changes to self-image and withdrawal from social situations. 170 Patients described difficulties in social interactions, attributing this to the reactions of 171 other people to their ptosis. Various behavioural strategies were described to 172 manage the responses of others and their own feelings about their ptosis. These 173 included forms of camouflage (for example, wearing dark glasses), avoiding 174 photographs and reducing eye contact. These are strategies reported in other 175 studies as typical of those with higher levels of social anxiety and lower self-esteem 176 and of those who anticipate negative reactions from others to their appearance (28) 177 (29) (30).

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179

180 looks normal. So if someone starts to take a photo I [had to] say hang on a minute,
181 I've got to turn around a bit."

(M; 27) "I worked out...an actual sort of angle I could look [at the camera]...so it

182

183 Differences were apparent in how male and female patients expressed the nature 184 and impacts of their appearance concerns. Women reported a greater level of worry 185 about how they were perceived by other people and also described the ways in 186 which ptosis affected their perceptions of themselves and their self-referent 187 emotions. Both of these aspects were reported as negatively impacting their self-188 esteem. Men were similarly concerned about the perceived negative judgements 189 made by others, but did not appear to internalize these to the same extent as 190 women. While men reported experiencing varying levels of social anxiety and

employing techniques to disguise the condition such as avoiding eye contact or
camouflaging their eyes, they did not report negative consequences for their selfperceptions or emotional well-being.

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(F; 62) "Because the result [of ptosis] was a one eyed monster. I looked absolutely
horrendous in photographs...If I looked in the mirror I'd think oh God, you're
hideous."

198

(M; 24) "Once they noticed it once, they'd notice it all the time...Obviously it did affect
my confidence slightly, yes because I never used to like having a conversation with
someone – I used to feel rude because I'd keep, I'd sort of look away so they
wouldn't notice."

203

204 The differences in the accounts of male and female participants' accounts may have

205 been influenced by broader social expectations. Men may have felt less able to

206 express any psychological impact of ptosis, downplaying any emotional

207 consequences and choosing instead to place the emphasis on the influence of the

208 condition on their behaviour in social situations.

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210 Theme 2 Lack of Awareness of Ptosis as a Treatable Condition: "I'd never even

211 heard the word ptosis."

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- 213 Although all participants reported a variety of problems with their eyes pre-
- 214 operatively, most were unaware of ptosis as a condition or available treatments prior

215 to their diagnosis. Over half of participants had been referred for surgery by their 216 optician, having previously believed that their ptosis was due to an untreatable 217 anomaly or the aging process. This raises the possibility that other potential patients 218 may also be unaware that they have a condition for which treatment is available. 219 220 (F; 66) "Never ever thought that I could have anything done. It was only the optician 221 that referred me on." 222 223 (F: 62) "It was after I'd been to the opticians because I'd never even heard the word

ptosis, let alone know I'd got it. And – oh I haven't got a droopy eye, I've got a
condition! And so just being told that actually made me feel better."

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Theme 3 Appearance Concern as Vanity and the Stigma of Cosmetic Surgery:
"I don't do cosmetic surgery…"

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230 When discussing their pre-operative appearance concerns, female participants 231 tended to present these as 'vain' and/or 'trivial', despite far-reaching psychosocial 232 impacts. To counter this, when describing their treatment to others, they insisted that 233 their treatment had not been 'cosmetic' surgery. In some cases, this perceived 234 stigma of 'cosmetic' surgery had prevented patients from seeking treatment earlier, 235 even when ptosis had caused major impacts to their lives. Some female participants 236 felt the need to excuse their appearance concerns, even though these had been a 237 significant driver in their desire for treatment.

238

(F; 62) "Oh, I hated it [ptosis]...But I would never have gone to the doctor. I just
assumed it was cosmetic surgery and that was vanity and that was tough...Because
I would have gone on believing it was cosmetic surgery and I wouldn't entertain
it...I've been waiting for someone to make a comment about me having had
cosmetic surgery and I'm ready for them!...I don't do cosmetic surgery, I don't
believe in it."

245

Regardless of gender, perceptions of surgery as cosmetic were cited as a main
factor in some participants decision-making regarding treatment, even where
negative impacts of the condition upon vision, appearance and/or well-being were
reported as significant.

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(M; 69) "I said I didn't want it done for cosmetic purposes, but if they thought it would
improve my vision, yes I wanted it done."

253

254 Some patients did not initially raise appearance changes as problematic, but in 255 further discussion revealed that the appearance element of ptosis had affected them 256 socially and/or emotionally. Similarly, when discussing the impacts of surgery, some 257 reported that improvements to appearance were of the greatest benefit, whereas 258 others wove functional and appearance aspects together. A reluctance to verbalise 259 appearance either as a prime motivator and/or the most positive consequence of 260 treatment was evident in several participants' accounts, even though the importance 261 of these issues was implied on many occasions.

262

The decision to seek treatment was more complex and multifaceted for some participants. This was particularly true for females, who discussed many factors contributing to their decision making, including their own opinions regarding cosmetic surgery, a reluctance to admit their concern about their eye appearance, a lack of knowledge of treatment, and the extent to which ptosis had impacted on their quality of life.

269

270 (F; 62) "And I said 'What's the point [of going to the GP]. It's cosmetic surgery. And

271 I'd written it off...as far as I was concerned it was part and parcel of the aging

272 process."

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Theme 4; Seeing Better and Feeling Better: "Getting back to the real world
again":

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277 All participants reported significant benefits following surgery, with no negative

278 consequences after the initial post-operative recovery. Reports of functional

improvements included better visual acuity, with many able to engage in daily tasks

which had been hindered by their ptosis.

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For the minority of patients, the functional gains were perceived to be the major benefit of treatment. However, many participants described improvements in other domains of life following surgical intervention, regardless of the extent to which deficits in vision had existed pre-operatively.

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Objective factors such as the age of the participant and the severity of their ptosis did not appear to be strongly related to participants' perceptions of the post-operative gains from ptosis surgery. Instead, those who reported the greatest benefits from treatment were those who reported significant negative impacts on their psychological well-being prior to surgery, in particular those with concerns about their appearance which had resulted in negative changes to self-image, selfconsciousness, social anxiety or social avoidance.

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(M; 24) "I used to try not to look at people square on for too long in case they noticed
it [ptosis]... [Surgery has] made me feel more confident when I'm going out, speaking
to people. I'll speak to them square on now and not sort of edge away or try to make
the conversation short so they don't notice it."

299

300 (M; 62) "[I can] talk to them now. Because I work in a place where there's probably

about seventy or eighty other staff, so I've got no problems with it at all now."

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301

303 (F; 62) "I wasn't that aware of [restricted vision due to ptosis] because my right eye
304 has never been good…I'm not ready to be old…[ptosis] was going to be the one
305 thing that was going to pull me kicking and screaming into being an old lady."
306
307 Discussion

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This study demonstrates that participants had experienced a range of negative impacts prior to surgery including functional deficits and compromised psychosocial well-being. Despite these impacts, several participants reported being reluctant to seek treatment due to concerns that others (including doctors) might perceive treatment as a 'cosmetic' procedure. The findings also illustrate the extent to which successful ptosis surgery can result in a range of positive patient reported outcomes, such as restoring social functioning and confidence, in addition to visual function.

Many of the psychosocial challenges associated with ptosis reflect those reported in studies of conditions which affect the appearance of the eye area(14) (15) (21). In this study, the majority of participants reported engaging in one or more of a variety of 'safety behaviours'(31) designed to minimize the noticeability of their ptosis to others and to protect themselves from possible negative reactions to their appearance. These included various forms of camouflage, minimizing eye contact, turning their head away, or shortening the length of their interactions with others.

325 Previous research has highlighted that a variety of emotional and psychological 326 processes can result in differences in the experiences of patients with appearance 327 altering conditions(32) (33). These include variation in the degree of importance 328 placed on the opinions of others and the extent to which appearance forms a part of 329 an individual's self-concept and self-esteem(34). In this study, the most notable 330 differences related to gender. Female participants reported greater pre-operative 331 negative emotional impacts of ptosis than men, with women detailing how the 332 condition impacted both their self-perceptions and their perceptions of how others 333 viewed them. However, this may be due to gender differences in reporting rather

335 exposure to images of idealized body shapes had negative impacts on both 336 genders, but only women reported an emotional impact. Previous research has also 337 highlighted gender differences in symptom reporting more generally. It is well 338 established that women report more numerous and more severe symptoms than 339 men, regardless of cause(35). These differences in disclosure have been attributed 340 to differences in male and female socialization and social roles(36) and to a 341 reluctance in men to admit how important their health and physical appearance are 342 to them(37). While these societal pressures and gendered factors may to some 343 extent explain the differences in reporting of pre-operative emotional consequences 344 of appearance concerns raised by participants in this study, no marked differences 345 between males and females were noted in terms of how they reported behavioural 346 responses to ptosis. In contrast, participants of both genders reported significant 347 post-operative benefits in visual functioning and psychosocial wellbeing. While some 348 reported improved vision as the major post-operative benefit, for many functional 349 improvements were secondary to the psychosocial benefits experienced following 350 successful surgery. These participants felt more confident in engaging socially 351 without experiencing social anxiety or anticipating negative attention or unsolicited 352 comments. The results clearly demonstrate that the benefits of ptosis treatment 353 extends beyond objective visual function, and can have a significant psychosocial 354 benefits. As this is a qualitative study with a small participant study, further research 355 is necessary to investigate gender differences in pre and post-operative reporting 356 more fully.

than to actual experience, with similarities to Cahill & Mussap's(32) findings that

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358 An interesting finding was that pre-operatively, some participants had thought of 359 treatment for ptosis as 'cosmetic', and that this had posed a potential barrier to 360 treatment. Similar themes have been found in patient accounts in relation to 361 treatment decision making following mastectomy. Some women expressed concerns 362 that others might perceive the choice to undergo breast reconstruction as self-363 indulgent and vain(38) (39), while others have reported regrets after reconstructive 364 surgery, as they felt they had made their decision for superficial reasons(40). The 365 view that 'plastic' surgery is synonymous with cosmetic surgery rather than with 366 reconstructive or restorative procedures is widespread within the media(1) (2) and 367 may be prevalent in some fields of medicine(41). British GPs' knowledge of plastic 368 surgery is limited by their lack of exposure to this specialty during training(42). 369 Furthermore, many types of eye surgery, (including for example, corrective 370 procedures for strabismus), have also been perceived to be 'cosmetic' procedures, 371 even within the eye care community itself(43). Therefore, the findings that this 372 perception may be shared by patients is unsurprising. 373 374 As previously noted, misconceptions are evident in resource allocation within the

NHS with marked regional variation(44). Currently, there are no published guidelines regarding treatment criteria for ptosis. The physical parameters employed by some CCGs to determine eligibility for treatment for conditions resulting in an unusual appearance fail to reflect the often considerable psychological and social impacts of appearance altering conditions. In the context of ptosis, the allocation of resources using only criteria relating to functional deficits fails to acknowledge the levels of

distress experienced by many in response to these challenges(45) (46) (19) and the
 potential gains in quality of life through the restoration of eyelid symmetry and an
 unremarkable appearance.

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385 Limitations of the study

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387 This is the first qualitative study which has explored patients' motivations for seeking treatment for ptosis, the impact of ptosis surgery and factors contributing to individual 388 389 differences in these processes in order to improve current understanding of patients' 390 experiences of ptosis surgery. In keeping with the qualitative design of this study, 391 interviews were conducted to the point at which no new concepts were identified 392 from the interview transcripts(47). This approach is especially useful when 393 investigating under-researched topics for which it is inappropriate to assume a pre-394 determined sample size . However, larger scale, quantitative research is necessary 395 to confirm the findings of this study in the broader population of patients undergoing 396 treatment for ptosis, particularly given that participants were recruited from one UK 397 site. It is possible that participants reported experiences are unique to this particular 398 patient group, or a reflection of the management of ptosis in one healthcare Trust. As 399 the inability to generalize results in any way other than a speculative form is a 400 feature of qualitative research in all forms, further, larger scale research is necessary 401 to underpin future recommendations to inform commissioning and practice. 402

403 Conclusion

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In conclusion, all participants in this study reported positive gains following
successful ptosis surgery, including functional and psychosocial improvements. The
restoration of symmetrical eyelids led to improvements in confidence and selfesteem, particularly in social situations. This study contributes to the growing body of
evidence attesting to the value of ptosis surgery in improving the function of the eyes
and psychosocial well-being of patients.

411 However, significant barriers to seeking treatment were cited, including a lack of 412 knowledge amongst potential patients and professionals about ptosis as a 413 diagnosable condition and the availability of corrective surgery. In addition, the belief 414 that requests for treatment might be interpreted as a desire for a cosmetic procedure 415 and the potential stigma associated with seeking treatment for reasons of vanity had 416 resulted in significant delays in seeking professional advice. Raising awareness 417 amongst those professionals who are the gatekeepers to referrals for assessment for 418 surgery (such as opticians and GPs) might go some way to reducing these barriers. 419 Finally, given that the results of this study suggest that surgery to correct ptosis 420 results in significant improvements in both function and guality of life. As such, 421 further larger scale studies are warranted with a view to informing recommendations 422 to Commissioners in relation to this intervention.

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Declaration of Interest

429 The authors declare no conflict of interest.

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