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Illness perceptions in people newly-diagnosed with glaucoma and ocular hypertension.

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Synopsis

Illness perceptions have strong links to outcomes in chronic disease. This study shows that some illness perceptions in newly-diagnosed patients with glaucoma or ocular hypertension differ to illness perceptions in patients who have been diagnosed for at least two years, overall illness perceptions were equally negative in all groups.

ABSTRACT

Background/aims: To determine whether self-reported illness perceptions in newly-diagnosed patients with primary open-angle glaucoma (POAG) and ocular hypertension (OHT) are more negative compared to peers who have lived with their diagnosis for more than two years.

Methods: A cross-sectional study of 58 newly-diagnosed patients with POAG and OHT recruited at their first clinic visit. Electronic patient records were used to identify similar patients (n=58, related by age and severity of visual field loss) who had their diagnosis for > 2 years. All participants completed the Brief Illness Perception Questionnaire (BIPQ), EQ5D general health measure and Type D Personality Scale (DS14).

Results: Average BIPQ scores were similar for people newly-diagnosed with POAG and POAG diagnosed > 2 years, and were no different to newly-diagnosed OHT and OHT diagnosed > 2 years POAG (p=0.46). An analysis correcting for personality type (DS14) and general health (EQ5D) indicated newly-diagnosed patients with POAG to have marginally better illness perceptions on individual BIPQ items quantifying impact on life in general, experience of symptoms and 'understanding' of their condition (all p<0.01). In contrast POAG patients with a diagnosis >2 years understood better their condition to be long-term (p<0.01).

Conclusions: Some illness perceptions differed between newly-diagnosed people and patients living with their diagnosis for >2 years. Illness perception for people with manifest glaucoma and at risk of glaucoma (OHT) were similar; the latter might benefit from an intervention at diagnosis that highlights the better prognosis for OHT compared to POAG.

Keywords;

glaucoma; ocular hypertension; chronic illness; illness perceptions; illness representations; lay beliefs of health and illness; self-regulation; illness cognitions.

INTRODUCTION

Illness perceptions are feelings or beliefs that influence a person's psychological response to their illness. These perceptions are, for example, associated with clinical outcomes, coping behaviours and adherence to treatment [1, 2]. A substantial body of research on illness perceptions in chronic disease exists but studies in people with primary open angle glaucoma (POAG) and ocular hypertension (OHT) are uncommon [3, 4, 5].

Interesting observations about negative illness perceptions at the point of diagnosis have been revealed in patients with POAG [6, 7]. Some of this negativity is likely attributed to the fear of going blind [8, 9]. Indeed, it has been shown that simply giving a diagnosis of POAG negatively affects measures of quality of life [8, 10]. Interviews with patients with POAG reveal initial feelings of fear were replaced by a more reasoned perspective over time [11]; this seems reasonable given most treated patients will not suffer significant visual impairment in their lifetime [12, 13]. Perhaps a newly-diagnosed patient may consider their condition will have a significant impact on them only to revise their view once they have the condition for a period of time; this has not been assessed in people with POAG/OHT. A better understanding of this idea has clinically relevant implications about how 'diagnosis' of POAG/OHT should be handled and communicated.

One way to examine illness perceptions in POAG would be to ask patients directly and subject the responses to qualitative analysis [7, 11]. Alternatively, patient reported outcome measures (PROMs) have been used to quantify illness perceptions in chronic conditions [14, 15]. Results from PROMs measuring illness perceptions have been linked to self-management behaviours, including attendance to follow-up appointments [16] and have also been shown to be related to decline in social and physical functioning [17, 18] in a variety of conditions. A widely used and validated PROM instrument is the Brief Illness Perception Questionnaire (BIPQ) [19, 20, 14]. We therefore use the

BIPQ in conjunction with other PROMs of well-being and personality allied to a measure of patients' visual function to assess patients' illness perceptions.

We aim to quantify illness perceptions in patients with POAG and OHT. Our primary hypothesis centres on newly-diagnosed POAG and OHT patients having worse illness perceptions when compared to a group of patients who have lived with a diagnosis for more than two years.

MATERIALS and METHODS

We used a cross-sectional study involving patients recruited from two clinical centres in England (Moorfields Eye Hospital NHS Foundation Trust (Bedford Hospital) and North West Anglia NHS Foundation Trust (Hinchingsbrooke Hospital)). Newly-diagnosed patients were introduced to the study at the end of the clinic visit at which they were first diagnosed. For the purpose of simplicity, in the methods and results we refer to these participants as cases. In addition, patients who had held a diagnosis of more than two years (but less than five years) were identified from an electronic patient record (EPR; Medisoft, Leeds, UK) used at the participating clinics. We refer to these participants as controls.

The study was approved by the North West - Liverpool East NHS Research and Ethics committee and it adhered to the tenets of the Declaration of Helsinki. All participants gave their informed written consent prior to taking part. Data was anonymised and stored securely.

Study participants (> 40 years) had a diagnosis of POAG or OHT established by standard ophthalmic examination in the participating clinics. Participants were only included if they had no other ocular disease (except for previous uncomplicated cataract extraction) and a visual acuity of better than 0.3 logMAR in each eye with astigmatism of less than 2 dioptres. All POAG participants had visual field (VF) loss in at least one eye as measured by a Humphrey Field Analyser (Carl Zeiss Meditec, Dublin, CA) using the Swedish Interactive Threshold Algorithm (Standard 24-2). Goldmann Applanation Tonometry was used to measure intraocular pressure.

Cases were identified by convenience sampling with an effort to select controls by 'matching' at a group level to age and VF severity (for POAG) to provide a representative cross section of patients. In other words, to allow for an age-related and disease severity-related analysis. In the POAG groups, mean deviation (MD) in the least affected eye (the eye with the better MD) was used as a measure

for disease severity [12]. This was taken from the VF recorded in the EPR at the time of diagnosis (cases) or at the time closest to the date when a questionnaire pack was returned.

A questionnaire pack, including a participant information sheet and consent form, was given to participants at the end of their clinic visit and returned by post; controls received and returned packs by post. Questionnaire packs included three validated instruments designed to measure illness perceptions, general health and personality type, respectively.

[1] Brief Illness Perception Questionnaire (BIPQ) - The BIPQ has been widely used to investigate illness perceptions in chronic illness [14, 15, 19]. Eight items are scored on a 0-to-10 scale with 80 representing the most negative illness perceptions. An open-ended styled ninth item asks patients to list the three most important causal factors for their illness. The original version of the BIPQ uses the word 'illness' but this was replaced by 'glaucoma' or 'ocular hypertension' for this study.

[2] EQ5D– The EQ5D-3L [21] is a commonly used general health PROM and is approved in the United Kingdom (UK) by the National Institute for Health and Care Excellence as a general health measure for health economic analysis. Five items are scored either 1 (no problems), 2 (some problems) or 3 (severe problems) on the domains of mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Codes were translated into an index score ranging from 1 (perfect health state) to -0.624 (worst health state) using an existing scoring system [22].

[3] Type D Scale personality questionnaire (DS14) – The DS14 is widely used to measure negative affect (e.g. general worry, gloom) and social inhibition (e.g. reticence, lack of self-assurance) [23]. This instrument has seven items for negative affect and social inhibition, respectively. Each item is scored from 0 (least distressed) to 4 (most distressed).

We hypothesised cases would have worse average BIPQ when compared to controls. Sample size calculations (with power and statistical significance set at 80 and 5% respectively) were based on

detecting a small 5-point (out of 80) difference in overall mean BIPQ score between cases and controls. Using an estimate of standard deviation (SD) of mean scores of 7.5 points from a previous study [19] gave a suggested minimum sample size of 28 participants per group, which was our recruitment target.

Data analysis

We compared mean BIPQ score, age, best eye MD (BEMD), worse eye MD (WEMD), EQ5D index score and DS14 between cases and controls for the POAG and OHT groups. All individual data distributions were checked for normality. Univariate association between overall BIPQ against age, DS14 and EQ5D index score was explored to assess covariance in the data.

Average score from each of the eight separate BIPQ items was also compared between cases and controls for the POAG and OHT groups using Multivariate Analysis of Covariance (MANCOVA); this corrects for any covariance from age, DS14 and EQ5D and is robust against multiple comparisons. A value of $p < 0.01$ was considered statistically significant to further reduce the possibility of a false positive result. The scores from the separate BIPQ items are not assumed to follow a normal distribution. Instead, residuals from the MANCOVA were examined for signs of non-normality to make sure the approach was valid.

Item 9 of the BIPQ asked participants, 'to list, in rank order, the three most important factors that you think caused your glaucoma/ocular hypertension'. Two authors (LM and DPC) independently coded the first written response into categories following a prescription used in previous research [19]. Any disagreements were arbitrated with a joint consultation by all authors and groupings of coded responses were assessed with descriptive statistics. All statistical analyses were done with SPSS Statistics 24 (IBM Corp., Somers, NY).

RESULTS

The recruitment period for the study ran from January to November 2015. Questionnaires were completed by 124 participants with eight excluded because of incomplete consent or unreliable VFs. Our final sample of participants (52% male) consisted of 58 cases and 58 controls. Participants were nearly all Caucasian (98%) with 93% educated to at least a high school level and 32% self-reporting degree-level or professional qualification.

POAG cases and controls were well related for age, BEMD, WEMD, and DS14 (Table 1). POAG controls had slightly worse average self-reported general health (EQ5D) when compared to POAG cases ($p=0.03$). For our OHT study groups the cases and controls were similar for age, EQ5D and DS14.

Table 1 – Mean (standard deviation) age, BEMD, WEMD, EQ5D index and DS14 for each of the four study groups.

	n	Age (y)	BEMD (dB)	WEMD (dB)	EQ5D Index	DS14
POAG Case	30	73 (9)	-4.8 (4.3)	-9.0 (4.8)	0.77 (0.22)	40 (11)
Control	31	71 (8)	-5.1 (5.1)	-9.2 (5.9)	0.89 (0.13)	36 (10)
		p=0.33	p=0.83	p=0.96	p=0.03	p=0.20
OHT Case	28	63 (10)	-	-	0.92 (0.11)	38 (10)
Control	27	65 (13)	-	-	0.86 (0.17)	36 (8)
		p=0.45	-	-	p=0.19	p=0.44

For our primary outcome, mean (standard deviation; SD) BIPQ score for POAG cases and POAG controls was 31 [10] and 34 (13) respectively; these values were not significantly different (independent t-test; $p=0.30$). Similarly, mean (SD) BIPQ score for OHT cases (28 [11]) and OHT controls (28 [9]) were not significantly different (independent t-test; $p=0.90$). These results indicate

that, on average, illness perceptions are similar in people newly-diagnosed compared to those that have their diagnosis for at least two years. Moreover, averages for all four groups were not different (one-way ANOVA; $p=0.46$). Therefore, on average, overall illness perceptions in this sample of people with POAG and OHT are similar.

There was no statistically significant association for BIPQ score against age ($r=0.11$; $p=0.29$). There was a weak but statistically significant univariate association for BIPQ against DS14 ($r=0.26$; $p=0.01$) and against EQ5D ($r=0.28$, $p=0.04$), suggesting illness perceptions are marginally worsened by a distressed personality and worse general health.

Estimated marginal means with 95% confidence interval (CI) give a sense of the distribution of scores for all eight individual BIPQ items (Table 2). Statistically significant differences between groups on each item are reported from a comparison of adjusted means using a MANCOVA adjusted for DS14 and EQ5D scores. In this analysis, statistically significant effects occurred in four items in POAG patients. These average effects were all small in magnitude, mostly less than an average of 2 points on a 10-point scale. The largest effect was for the item about how long a participant thought POAG will last. In comparison to newly-diagnosed patients, people with POAG for >2 years better understood their condition will last for a 'long time'. In comparison to newly-diagnosed patients, people with POAG for >2 years feel slightly more affected by the condition and experienced more symptoms. The latter is interesting given disease severity in the two groups was similar on average. Perhaps surprisingly, newly-diagnosed patients claim to understand their condition slightly better than those who have had POAG for >2 years. There were no statistically significant differences between cases and controls for people with OHT on any of the BIPQ items.

Some of the average values for items (Table 2) are noteworthy. For example, most participants understood their POAG/ OHT is going to last for ever but a number did not. There was also a wide response to the question about control over POAG/ OHT revealing that many participants felt they did not have good control over their condition.

Table 2 – MANCOVA results for differences between POAG cases and controls, and OHT cases and controls for the eight items of the BIPQ. Mean scores (out of ten) shown are estimated (marginal) means and 95% confidence interval (CI), adjusted for DS14 and EQ5D index scores. The p values marked with * denote a significance level of <0.01

	POAG	Estimated marginal mean (95% CI)	p	OHT	Estimated marginal mean (95% CI)	p
How much does your OAG/OHT affect your life? (1=little affect)	Case	1.2 (0.4, 2.0)	<0.01*	Case	1.2 (0.7, 1.8)	0.90
	Control	3.4 (2.6, 4.1)		Control	1.3 (0.7, 1.9)	
How long do you think your OAG/OHT will continue? (10 = a long time)	Case	7.0 (5.9, 8.0)	<0.01*	Case	6.1 (4.8, 7.4)	0.28
	Control	9.4 (8.4, 10.4)		Control	7.2 (5.8, 8.6)	
How much control do you think you have over your OAG/OHT? (1=little control)	Case	4.5 (3.1, 5.8)	0.92	Case	5.6 (4.2, 7.0)	0.29
	Control	4.6 (3.3, 5.9)		Control	4.5 (3.0, 6.0)	
How much do you think your treatment can help your OAG/OHT? (10=very helpful)	Case	2.6 (1.7, 3.6)	0.25	Case	2.8 (1.8, 3.7)	0.38
	Control	3.4 (2.5, 4.3)		Control	3.4 (2.4, 4.4)	
How much do you experience symptoms from your OAG/OHT? (1 = few symptoms)	Case	1.0 (0.3, 1.7)	<0.01*	Case	1.2 (0.5, 1.9)	0.86
	Control	2.7 (2.0, 3.3)		Control	1.3 (0.5, 2.1)	
How concerned are you about your OAG/OHT? (10 = very concerned)	Case	5.2 (3.9, 6.5)	0.33	Case	4.7 (3.6, 5.8)	0.33
	Control	6.1 (4.9, 7.4)		Control	3.9 (2.7, 5.1)	
How well do you think you understand your OAG/OHT? (1= little understanding)	Case	5.9 (4.9, 6.9)	<0.01*	Case	4.4 (3.3, 5.5)	0.20
	Control	3.9 (3.0, 4.9)		Control	5.5 (4.3, 6.7)	
How much does your OAG/OHT affect you emotionally? (10=very emotional)	Case	1.6 (0.7, 2.5)	0.05	Case	2.0 (1.3, 2.7)	0.39
	Control	3.1 (2.3, 3.9)		Control	1.5 (0.8, 2.3)	

One-hundred and six (91%) participants gave at least one written response to the open-ended item asking for the three most important causes (in rank order) for POAG/OHT. We only considered the

first written response in the list where participants (n=46) gave more than one cause. The summary of the coded responses, stratified by cases and controls, are shown in Table 3. Most cases (60%; 95% CI 45 to 74%) and controls (59%; 95% CI 45 to 72%) who completed item 9 correctly identified at least one known major risk factor [24]. It is noteworthy that 5% (95% CI 1% to 11%) of control participants, despite living with their diagnosis >2 years actively wrote, “don’t know” when asked for the cause of their condition.

Table 3 – Frequency of responses by group to Q9 of the BIPQ [19], ‘Please list, in rank order, the three most important factors that you think caused your glaucoma/ocular hypertension’.

	Case (n = 50)	Control (n=56)
Hereditary/Genetics – it runs in my family	19 (38%)	26 (46%)
Aging	8 (16%)	4 (7%)
Elevated intraocular pressure	3 (6%)	3 (5%)
Don’t know	1 (2%)	3 (5%)
Other conditions (including other eye disease)	5 (10%)	8 (14%)
Chance or bad luck	8 (16%)	3 (5%)
My own behaviour (including not seeing an optometrist regularly)	4 (8%)	1 (2%)
My emotional state (e.g. anxiety, stress, worry)	0 (0%)	3 (5%)
Lifestyle (e.g. smoking, reading, living in Asia)	2 (4%)	5 (9%)

DISCUSSION

In a cross-sectional study we used an established method of measuring illness perceptions [19] to investigate average differences between newly-diagnosed POAG/OHT patients (cases) and those with a diagnosis of more than two years. Results indicate no difference in overall illness perceptions between the cases and those with a diagnosis of more than two years. Therefore, perhaps surprisingly, in this group of people, a new diagnosis of POAG/OHT does not precipitate a sudden feeling of negative illness perceptions when compared to other people who have lived with the condition for more than two years.

Our findings represent new knowledge about illness perceptions in people with POAG/OHT. For example, results suggest diagnosis may not be as distressing as previous studies have indicated [6, 7, 10]. Overall illness perceptions of our participants were, for example, similar to those from other studies that have used BIPQ to assess heart palpitations [14] or pre-treatment pulmonary tuberculosis [15]. In contrast, scores were lower on average than those found in people with diabetes [19]. These comparisons allow illness perceptions of POAG/OHT to be placed on a spectrum of chronic disease, but it may not be meaningful because of differences in the type of study and study populations.

Secondary analysis of individual BIPQ items, when corrected for patient's level of distressed personality (measured by DS14) and self-reported general health (measured by EQ5D) revealed interesting results. Unsurprisingly, newly-diagnosed POAG patients held less realistic beliefs about their condition compared to people who had the diagnosis >2 years. Moreover, newly-diagnosed POAG patients reported having less severe symptoms compared to those who had the diagnosis >2 years, despite the two groups having similar average VF loss. In addition, POAG patients with a diagnosis for > 2 years had a more realistic perception of how long their illness would last compared to those newly-diagnosed. Remarkably, around one-third of the latter scored less than five on this item, indicating that they felt their condition would not last a long time. Other studies, in other

conditions, suggest patients who do not understand their illness to be long term are more likely to abandon their treatment programmes when compared to those who comprehend their illness to be chronic [25, 26]. This suggests more should be done, at the point of diagnosis, to make sure patients are aware that their condition is permanent.

POAG cases reported they understood their condition better than those with a diagnosis of more than two years and this was unexpected. Perhaps though this might be explained by the very recent information received about POAG during diagnosis. In addition, patients' causal beliefs were also interesting; the majority of participants could identify a "true" risk factor for POAG and OHT [24] but many also held untrue causal beliefs. Many patients correctly understood POAG/OHT to be largely idiopathic and this warrants further study because work in other chronic conditions has shown this perception can influence prognosis [27].

Beliefs about control over POAG/OHT varied widely with, for example, many patients returning low scores on questions about how much treatment can help. This may have arisen because of confusion over illness cures rather than illness control. Yet, a negative outlook about treatment potential has been shown to impact on well-being and adherence to treatment in other chronic disease [28, 29, 30]. Patients who do not think their medication is useful may not take it, especially if they also feel that their condition is not long-term [31]. This finding reinforces the importance of communicating the important message about necessity of adhering to a life-long treatment to people with POAG/OHT.

A notable finding is the similarity in illness perceptions between patients with ocular hypertension (OHT) and manifest glaucoma (POAG). Long-term prognosis for OHT patients is relatively good, with only a small number developing POAG [32]. Our findings indicate OHT patients may need different information at diagnosis to help improve perceptions surrounding the consequences of their illness and to make sure they understand their diagnosis is different to a diagnosis of manifest glaucoma.

Our study had several strengths. For example, the cases and those with a diagnosis of more than two years were stratified and related by age and disease severity. Patients with any other significant ocular co-morbidity were excluded to help ensure that BIPQ scores were reflective of the patients' experience of their POAG/OHT. Moreover, our analysis took account of self-reported general health (albeit with a relatively blunt tool [EQ5D]) and distressed personality as confounders of response to BIPQ. Furthermore, sample sizes were large enough to support our finding of no differences in average BIPQ across our groups. Newly-diagnosed patients were recruited by the same clinician at diagnosis, ensuring continuity of information but this did not allow for testing of variation in response if, for example, diagnosis had been given by different doctors.

There are several limitations to our study. People were only recruited from two clinical centres in England, were nearly all Caucasian and a significant proportion were well educated, to a graduate or professional level. Previous studies have found racial differences in illness perceptions [33] but there is evidence that general education level may not be associated with illness perceptions [34]. Our results may have been subject to volunteer bias too; we did not collect data on people who chose not to participate or who did not return questionnaires packs. Moreover, we did not record information about patients' co-morbidities and many elderly people have more than one chronic illness [35]. Still we mediated this limitation by using a measure of self-reported general health (EQ5D) [36] and corrected our analyses for this.

Findings from this study suggest avenues for future research. Investigations into treatment beliefs may lead to important information to improve adherence rates to medications as suggested by another study in people with glaucoma [37]. A study exploring, in more detail, self-reported outlook and prognosis for people with OHT and how this ought to differ from patients diagnosed with glaucoma with VF loss would be interesting. A follow-up study to look at the impact of more detailed post diagnosis education would be worth considering, especially as the BIPQ scores for "how much control do you think you have over your OHT/OAG" and "how much do you think your treatment can

help you OHT/OAG” were disappointingly low. A study examining a wide demographic of patients from different clinical centres would be useful. Moreover, a cohort study could follow the same patients to investigate changing illness perceptions in the same individuals over time.

To conclude, overall illness perceptions in newly-diagnosed patients are similar to those with more experience of the condition in glaucoma and ocular hypertension. There were some differences on individual domains of the BIPQ, notably the experience of symptoms and beliefs about how long the illness would last; for example, many newly-diagnosed POAG patients do not realise their condition permanent. Remarkably, people with a diagnosis of OHT had similar negative illness perceptions as those people with manifest glaucoma; this is an important finding given the long-term risk of visual impairment associated with glaucoma is different to those with OHT. The negative perceptions held by OHT patients may highlight the need for better communication about the nature of their diagnosis and prognosis.

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