Self and Others:

An Exploration of Chronic Open-angle Glaucoma as a Chronic Illness

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A thesis submitted for the degree of Doctor of Philosophy

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List of Abbreviations

COAG – Chronic Open-angle glaucoma

VF – Visual field

ONH – Optic nerve head

OHT – Ocular hypertension

ACG – Angle-closure glaucoma

NTG – Normal tension glaucoma

RGC – Retinal ganglion cell

VA – Visual acuity

QoL – Quality of Life

BIPQ – Brief Illness Perception Questionnaire

MCSI – Modified Caregiver Strain Index

EQ-5D – EuroQol-5 Dimension

ICG – Informal caregiver

IPA – Interpretative phenomenological analysis

CAIs – Carbonic anhydrase inhibitors

SLT – Selective laser trabeculoplasty

ALT – Argon laser trabeculoplasty

MIGS – Minimally invasive glaucoma surgeries

NEI-VFQ-25 – National Eye Institute Visual Function Questionnaire – 25

CSM – Common-sense model of illness representations

PROMs – Patient reported outcome measures

EPR – Electronic patient record

DS14 – Type D personality questionnaire

BEMD – Best eye mean deviation

WEMD – Worst eye mean deviation

CI – Confidence interval

IOP – Intraocular pressure

RNFL – Retinal nerve fibre layer

NICE – National Institute for Health and Care Excellence

WHO – World Health Organisation

OCT – Optical Coherence Tomography

mmHg – Millimetres of mercury

GAT – Goldmann applanation tonometry

CDR – cup-to-disc ratio

SAP – Standard automated perimetry

HFA – Humphrey field analyser

dB – decibels

SITA – Swedish interactive threshold algorithm

PSD – Pattern standard deviation

SD – Standard deviation

MD – Mean deviatio

MANCOVA – Multivariate Analysis of Covariance

IGA – International Glaucoma Association

UK – United Kingdom

TIPI – Ten Item Personality Inventory

IQR – Interquartile range

AMD – Age-related macular degeneration

GTCAT – Glaucoma Treatment Compliance Assessment Tool

MMSE – Mini Mental State Exam

HBM – Health Belief Model

ETDRS – Early treatment diabetic retinopathy study

This work is dedicated to my niece, Isabelle, who was born with glaucoma secondary to aniridia in 2015. You and Emily are a constant source of pride and motivation, thank you.

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Declaration

The work contained in this thesis was completed by the candidate Leanne McDonald (LM), under the supervision of Professor David Crabb. It has not been submitted for any other degrees, either now or in the past. Where work contained in this thesis has been published previously, this has been stated in the text. All sources of information have been acknowledged and the appropriate reference given. The University Librarian of City, University of London is permitted to allow this thesis to be copied in whole or in part without reference to the author. This permission covers single copies made for study purposes, subject to normal conditions of acknowledgement.

Abstract

Chronic Open-angle Glaucoma (COAG) is a disease affecting the optic nerve, which can cause slow and irreversible sight loss. Once diagnosed, COAG requires lifelong monitoring in a hospital setting. The four studies presented within this thesis aimed to explore the experience of living with COAG through investigating some of the cognitive and emotional processes of patients and their informal caregivers (ICG). In the first study (cross-sectional) illness representations in 58 newly diagnosed patients with COAG were similar to 58 peers who had been diagnosed for > 2 years. The main outcome was the Brief Illness Perception Questionnaire (BIPQ). Analysis correcting for personality type (DS14) and general health (EQ-5D) indicated newly diagnosed patients to have marginally better illness representations on individual BIPQ items quantifying impact on life in general, experience of symptoms and 'understanding' of their condition (all $p<0.01$). In contrast, patients with COAG with a diagnosis >2 years understood better their condition to be long-term ($p<0.01$). The second study (longitudinal feasibility) tested the hypothesis that patients could self-monitor their COAG using a web-based diary tool. Ten volunteers were prompted to monitor symptoms every three days and complete a diary about their vision during daily life using a web-based diary tool over an 8-week period. Completion rate to items was excellent (96%). Themes from a qualitative synthesis of the diary entries related to behavioural aspects of glaucoma. Patients reported a variety of important life changes due to their COAG, such as increased frustration and cessation of activities as well the importance of social support and clinician trust as protective factors for their wellbeing. The third study (cross-sectional) investigated the factors which may lead to an increased reliance on ICG. A modified version of the Caregiver Strain Index (MCSI) was used to investigate ICG strain. In the patients with an ICG, 87% (33/38) self-reported they were married or in a committed relationship as opposed to being single, divorced, widowed or separated; 60% (40/67) in the patients who did not have an ICG ($p=0.004$). Percentage of patients with an ICG was also much higher in patients with advanced VF loss (82%; 9/11) when compared to those with non-advanced VF loss (31%; 29/94; $p=0.001$). Mean (standard deviation) MCSI was considerably inflated in the advanced patients (5.6 [4.9] vs 1.5 [2.2] for non-advanced; $p=0.040$). Worsening VF and poorer self-reported EQ-5D were associated with worsening MCSI. The final study (focus groups) used interpretative phenomenological analysis (IPA) to investigate experiences of ICG. Experiences of patients with ICG and patients without ICG were compared. Participants without an ICG feared a loss of independence more than those with an ICG. Those with an ICG stressed the importance of their ICG being involved in communicating with care teams and administering medications. ICGs felt a sense of obligation toward the patient, but this was not generally associated with negative emotions. To conclude, these studies demonstrate new knowledge on the complexities of the cognitive and emotional processes involved in living with COAG, including the importance of both the patient and their support network in forming and maintaining positive attitudes toward health and illness. Results from this thesis may inform a more integrated approach to COAG clinical practice, encompassing both the patient and their ICG.

Chapter One - Introduction

"I am not what has happened to me, I am what I choose to become."

- Carl Gustav Jung

The aim of this PhD thesis is to explore the experience of living with Chronic Open-angle Glaucoma (COAG). Specifically, to investigate the cognitive and emotional processes involved in adaptation to COAG as a chronic illness from the perspective of both the patient and their immediate social support network (informal caregivers). In order to clarify the aims of this work, this chapter gives a summary of relevant background literature. Further details on the specific aims of the thesis are outlined at the end of **Chapter One**.

1.1 Glaucoma Definition and Background

Glaucoma is the name given to a group of chronic diseases whereby the optic nerve sustains damage over time, affecting a patient's visual function. Damage caused by glaucoma is irreversible; indeed, it is the second most common cause of irreversible blindness in the developed world (Bourne, et al., 2018). An estimated 60.5 million people have experienced a loss of vision caused by glaucoma, with 4.5 million people developing bilateral blindness (blindness in both eyes) as a result (Quigley & Broman, 2006). Glaucoma has no cure, although appropriate long-term treatment and monitoring can halt or slow disease progression (Lee & Higginbotham, 2005). In the UK, Chronic Open-angle Glaucoma (COAG), which is the most common subtype, affects around 2% of people over the age of 40, with prevalence rising to 10% of people over the age of 70 (King, Azuara-Blanco, & Tuulonen, 2013). Due to the increase in life expectancy in developed countries and the number of people with glaucoma is

expected to reach ~80 million by 2020 (Quigley & Broman, 2006). COAG is sometimes referred to as the 'silent thief of sight' because it is usually asymptomatic in its early stages. This means that as many as 22-25% of patients already have advanced vision loss when they present to eye services for the first time (Crabb, Saunders, & Edwards, 2017). Visual impairment from COAG (measured by loss in the visual field, [VF]) has been linked to restricted mobility and activities of daily living, falls and a reduction in Quality of Life ([QoL] Crabb, 2016). A rise in the number of COAG cases, many of whom may already have advanced vision loss and impacted QoL on presentation, is likely to lead to increased demands on already strained hospital eye care services. The increase of cases could potentially cause detrimental effects on patient wellbeing.

1.1.1 Glaucoma Subtypes and Risk Factors

The term '*glaucoma*' is often used synonymously with COAG, but glaucoma is actually a group of neurodegenerative diseases, each with different characteristics. Glaucomas are classed as 'primary' or 'secondary', with the latter term referring to cases where optic nerve damage has occurred as a result of other ocular disease. The primary risk factors for glaucoma are age (King, Azuara-Blanco, & Tuulonen, 2013), ethnicity (Quigley & Broman, 2006), family history of the disease, thinner central corneal thickness and higher intraocular pressure (Coleman & Miglior, 2008).

Primary glaucomas, including COAG, affect around 60.5 million people worldwide (Quigley & Broman, 2006). This means that COAG affects around 2-3% of adults over 40, increasing exponentially to between 10-20% of adults

over 70, with African and Latin American populations being disproportionately affected(Quigley & Broman, 2006). COAG typically occurs because of a gradual or sustained increase in intraocular pressure (IOP), which causes progressive damage to the optic nerve head (ONH). This in turn causes the patient to lose vision in their visual field (VF). Estimates of the average rate of VF loss in COAG vary but typically progression of more than -1.5dB a year is considered problematic (Saunders, Medeiros, Weinreb, & Zangwill, 2016). Once a patient has been diagnosed with COAG, they require lifelong monitoring of their condition.

Some patients will sustain ONH damage and VF loss similar to COAG patients, but whilst their IOP measurements remain within normal range. This variant is called normal tension glaucoma (NTG). It is not known how damage occurs in people with NTG (Bell & O'Brien, 1997). The data collected and utilised in this thesis relate to COAG and NTG, with no distinction made between the two since the treatment and monitoring are identical.

Angle closure glaucoma (ACG) is another form of primary glaucoma which generally progresses faster than COAG and often constitutes a medical emergency. Around a third of primary glaucoma cases are ACG (Quigley, 1996). ACG affects around 0.5% of the worldwide population over the age of 40 and whilst ACG prevalence remains relatively stable in Caucasian and African populations, it increases to around 2-5% of over 70's in South East Asian populations (Quigley & Broman, 2006). The process of harm in ACG can happen in two ways. It may occur as a sudden attack (acute angle closure), which manifests as a sharp pain in the eyes, accompanied by blurred vision, nausea

and a headache, or as a progressive disease, similar to COAG, but with patients typically progressing at a rate of around -2dB per year (Lee, Kim, & Hong, 2004). Most ACG patients will be offered laser or surgical interventions, although acute angle closure requires emergency surgical treatment to open the drainage angle.

There are also several secondary glaucoma's, which occur because of other ocular or systemic disease. Examples of these include exfoliative glaucoma, neovascular glaucoma and some forms of glaucoma which occur in babies and are caused by malformation of the anterior segment in utero, these forms of glaucoma are often visible to the naked eye or on inspection of the anterior chamber (see **Figure 1.1**)

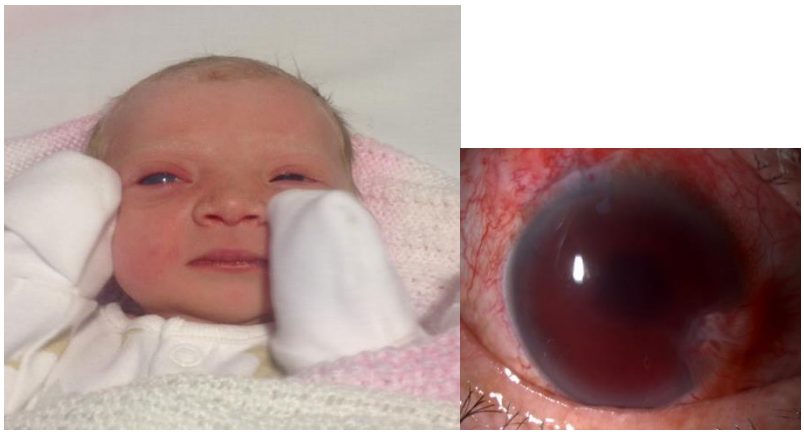

Figure 1.1: Left: *A new-born with secondary congenital glaucoma due to incomplete formation of the anterior segment (source: author's own image).* Right*: A patient with neovascular glaucoma where new blood vessels develop in the iris/anterior segment (source: https://www.meduweb.com/threads/3686-Neovascular-glaucoma).*

1.1.2 Biological Basis of Glaucoma

The exact pathophysiology of glaucoma remains speculative but it is thought that damage to the optic nerve head (ONH) occurs through the loss or death of retinal ganglion cells (RGC), which leads to a reduction in light sensitivity in the VF (Casson, Chidlow, Wood, Crowston, & Goldberg, 2012). To understand how RGC loss relates to a reduction in light sensitivity, it is necessary to understand how light is processed by the human eye. In short, light waves enter the eye through the cornea and are projected on to the retina. The retina is a thin band of tissue consisting of layers of cells which lines the back of the eye (see **Figure 1.2**).

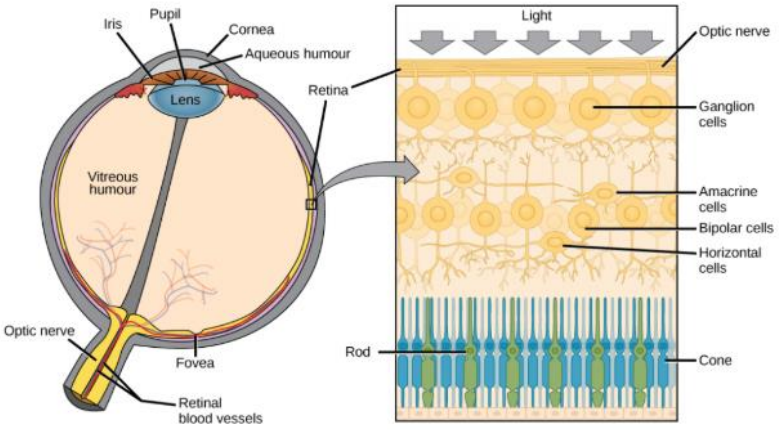

Figure 1.2: *The key landmarks of the human eye (left) and retina (right) (source: https://www.oercommons.org/courseware/module/15125/student/?task=3).*

RGC's are responsible for receiving light signals from the rod and cone cells (collectively known as the photoreceptors) and transmitting them down the ONH where the information can be processed in the visual cortex (Masland, 2012). The layer of RGC axons responsible for transmitting light signals is called the retinal nerve fibre layer (RNFL). In glaucoma, the axons in the RNFL are

damaged which leaves them unable to process or communicate the signals, resulting in a reduction of sensitivity.

The reason that the RNFL is affected in glaucoma is not fully understood but it is thought that increases in RGC death and subsequent visual damage may occur because of high intraocular pressure (IOP) (Guo, Moss, Alexander, Ali, Fitzke, & Cordeiro, 2008). In the eye, pressure is controlled by the balance of aqueous humour, which is a clear watery fluid that circulates through the anterior chamber (the front section of the eye), next to the iris and cornea (see **Figure 1.2**). The aqueous humour is drained away through a series of small channels, which are called the trabecular meshwork. Sometimes there is a disturbance between the inflow and outflow of the aqueous humour, causing an elevation in IOP. Elevated IOP (defined clinically as more than or equal to 24mmHg) is a key criterion for referral from primary care services (community optometrists) to secondary care services (hospital clinics) for suspected glaucoma (National Institute for Health and Care Excellence, 2017). Around 10% of patients referred to glaucoma services in the UK will be diagnosed with ocular hypertension (OHT) (Chan, et al., 2017), defined as sustained IOP more than or equal to 24mmHg but without damage to the VF. Around 4% of patients diagnosed and on treatment for OHT go on to develop COAG (Gordon, Beiser, & Brandt, 2002), compared with around 10% of those who are untreated.

The resulting damage to RGCs leads to areas of the retina becoming less sensitive to light. These patches of poor vision are referred to as a 'scotoma' (*plural; scotomata*). Patients with COAG usually do not lose light perception in the areas of their vision that are affected, and so do not view these patches as

blackness but rather as blurred or missing patches in their vision (Crabb, Smith, Glen, Burton, & Garway-Heath, 2013). This is particularly important for our understanding of why more than 50% of COAG remains undiagnosed in the developed world (Quigley, 1996). COAG is often unilateral to begin with, meaning that it affects one eye before the other in around 66% of new cases (Heijl, Bengtsson, & Oskarsdottir, 2013). Human vision however, is binocular, meaning that both eyes work together and the least affected/unaffected eye compensates for the scotoma in the affected eye, making the vision loss imperceptible in the early stages of the disease (Safran & Landis, 1999).

1.2 Diagnosing and Monitoring Glaucoma

Due to the progressive nature of COAG and the likelihood that the patient does not notice their early VF loss, most new COAG patients are identified during routine optometric examinations (Lawrenson, 2013). Patients who have suspected COAG are referred to hospital eye care services, where around 10% will be diagnosed with OHT (Chan, et al., 2017) and ~40-50% will be diagnosed with COAG (Salmon, Terry, Farmery, & Salmon, 2007). The most common causes for referral to secondary care are abnormalities in ONH images (~30%), elevated IOP (~26%) or a combination of these two parameters (~17%) (Salmon, Terry, Farmery, & Salmon, 2007). In a secondary care (hospital) setting, COAG is diagnosed using a combination of gonioscopy, which allows examination of the anterior chamber angle, measurement of IOP through tonometry, imaging of the ONH using slit lamp bio microscopy or optical coherence tomography (OCT) and tests of visual function, including VF and visual acuity (VA). Once diagnosed, patients will attend a m..onitoring visit approximately once every six to twelve months for the remainder of their lifetime (National Institute for Health and Care Excellence, 2017).

1.2.1 Gonioscopy

Gonioscopy is used to evaluate the internal drainage system of the eye. This internal drainage system is called the 'anterior chamber angle' and it contains the trabecular meshwork, a series of channels which the aqueous humour drains from. A special lens prism is placed onto the cornea and allows the clinician to look at the drainage angle and assess its functionality (Boyd, 2019). The appearance of the drainage angle is used to determine the type of glaucoma

that the patient may have. An open drainage angle may be indicative of COAG, whereas an angle that appears closed or narrow is indicative of ACG.

1.2.2 Tonometry

Although an elevated IOP can occur in isolation and may not be indicative of the presence of VF damage, it is the only modifiable risk factor for COAG progression and a useful clinical measurement in glaucoma clinics. The IOP value is measured during a procedure called *tonometry.* Tonometry measures the level of force in grams (which is then converted to millimetres of mercury (mmHg), which is required to flatten the cornea. Pressure is applied either indirectly using an air pulse (non-contact) or directly using a probe on the cornea (contact). The reference standard in ophthalmology is Goldmann applanation tonometry (GAT), a form of contact tonometry. In GAT, the clinician uses small probe to flatten an area of the central cornea.

GAT measurements may be biased by the structure of the eye. For example, patients with thin corneas often have artificially lower IOP readings (Medeiros & Weinreb, 2012). There are also many patients who have NTG, where there is the presence of glaucomatous damage without elevated IOP(Bell & O'Brien, 1997). For these reasons, IOP measurement, although a useful predictive tool, cannot be used as the sole tool for establishing the presence of glaucoma or monitoring progression.

1.2.3 Measurement of structural change

The health of the ONH and RGCs are key diagnostic criteria for COAG, as well as a useful indicator of progression. This is because changes can occur to the ONH long before any changes in vision can be observed (Weinreb & Khaw, 2004).

The health of the ONH is analysed in two ways. Clinicians may use a slit lamp to look at the ONH directly or use optical coherence tomography (OCT) to create images of the ONH and RNFL(National Institute for Health and Care Excellence, 2017). When using a slit lamp, clinicians primarily look for changes to the ONH, including its colour and the pattern of blood vessels within the eye. The ONH has a small 'cup' at the centre, which is surrounded by a rim of RNFL tissue (the neuro-retinal rim). Clinicians measure changes to the ONH using the cup-to-disc ratio (CDR). A good analogy for the CDR is the size of a doughnut hole. If the hole occupies 2/10 of the entire diameter of the doughnut, the CDR would be 0.2 whereas, if the hole occupies 7/10 of the doughnut, the CDR would be 0.7. A typical non-glaucomatous CDR is less than 0.4, however there is individual variation. A CDR of >0.8 indicates that a disc should be treated as glaucomatous until proven otherwise (Tsai, 2005). In addition to calculating CDR, clinicians look for changes to the colour of the optic disc and changes to the RNFL, which become paler and thinner respectively (see **Figure 1.3**).

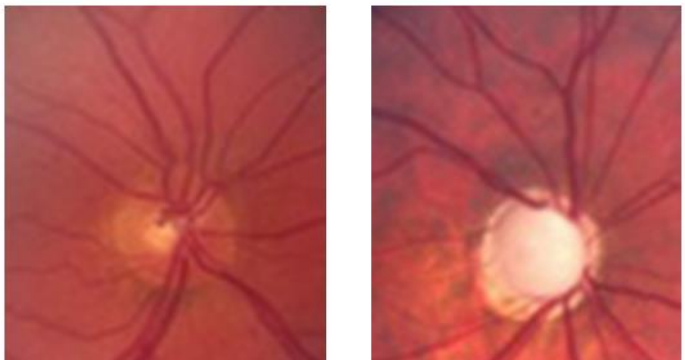

Figure 1.3 *A comparison of a healthy optic nerve head (left) and a glaucomatous optic nerve head (right). Severe optic disc cupping and disc pallor can be seen in the glaucomatous disc (source: author's own images).*

Due to the high intra-observer and inter-observer variation in assessment of the ONH when assessing the health using a slit lamp (Gaasterland, et al., 2001), the clinician will also take images of the ONH and RNFL using OCT. OCT is a non-invasive procedure which provides three-dimensional, high resolution images of the ONH and RNFL, and provides cross sections so that the thickness of the RNFL can be assessed. OCT machines compare the scanned eye to other eyes in an in-built normative database in order to provide the clinician with an estimate of whether the eye is glaucomatous. RNFL and ONH imaging using OCT provides high quality reproducible images and is highly sensitive for detecting changes in the CDR and RNFL thickness (Kotowski, Wollstein, Ishikawa, & Schuman, 2014).

1.2.4 Visual Fields

Understanding of physiological damage in glaucoma is very valuable, however measures of visual function are also important for understanding the impact of COAG on the patients' ability to see well in their day to day lives. Perhaps the most important method of assessing visual function in COAG is measurement of the VF. VF testing is the method used to detect scotomata and thus is a vital component for the diagnosis and monitoring of COAG.

The visual field can be defined as the entire space a person or animal is able to see when the eye is fixed in a central position. A 'normal' VF usually covers an area of approximately 60° down and 70° up and 90° temporally and 60° nasally from the point of fixation (Henson, Chaudry, Artes, Faragher & Ansons, 2000). The VF test looks at light sensitivity at different points on the retina. Light

sensitivity can be described using a 'hill of vision' analogy. Sensitivity is highest at the point of fixation and gradually decreases as the light reaches the more peripheral points of the VF (see **Figure 1.4**). The functionality of the VF is assessed using a procedure called perimetry.

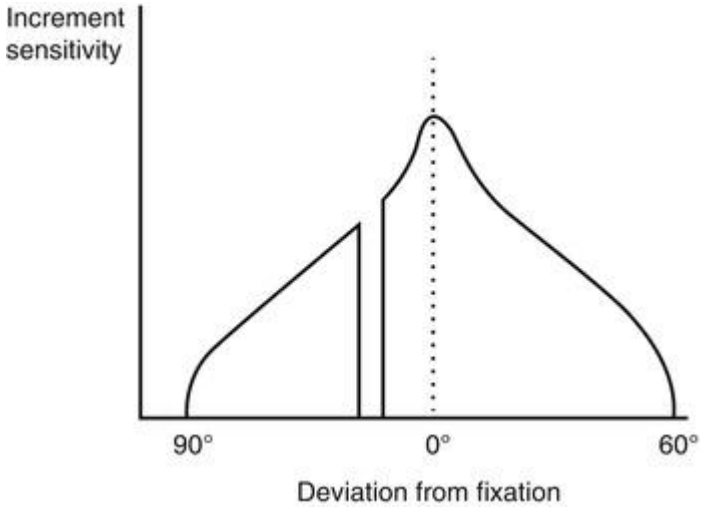

Figure 1.4: *A 2-dimensional representation of the hill of vision. The 0° point represents the point of fixation. We can see that sensitivity decreases in the peripheral retina (source: https://entokey.com/the-visual-field/)*

Standard automated perimetry (SAP) is regarded as the gold standard for diagnosis of COAG(National Institute for Health and Care Excellence, 2017). Two of the most common standard automated perimeters are the Octopus (Interzeag AG, Schlieren-Zurich, Switzerland) and the Humphrey Field Analyzer (HFA, Carl Zeiss Meditec Inc., USA).

The HFA (see **Figure 1.5**) is the most commonly used in the UK and was the perimetry method used for the studies described within this thesis. During HFA examination, the patient places their head on the chin/forehead rest at a fixed distance of 33cm and looks into the 'bowl', which has a luminance of 10cd/m^2.

Light stimuli from 0.025 to 3183cd/m^2 are projected onto different areas of the retina according to the algorithm chosen by the clinician. The patient is required to fixate at a central point and press a button each time they detect a light stimulus. The lowest luminance level, measured in decibels (dB), which is detected by the patient at each point in the field, is used as the sensitivity threshold.

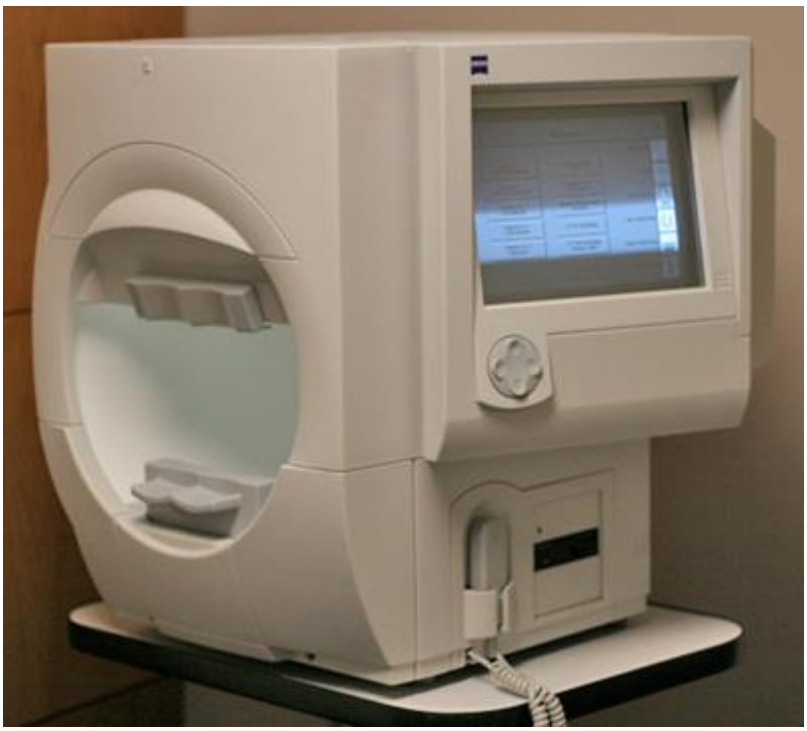

Figure 1.5: *A Humphrey Field Analyzer (source: The Melbourne Eye Centre: http://melbourneeyecentre.com.au/glaucoma/diagnosing-glaucoma/).*

Generally, clinicians use a standard 24-2 Swedish Interactive Threshold Algorithm (SITA standard 24-2) to detect and monitor glaucoma. This test measures 24° temporally, and 30° nasally of the fixation point. The HFA compares the patient's responses to white-on-white light stimuli with an age-matched normative database and any reductions in sensitivity indicate a VF

defect in that location. A mean sensitivity of 30-35dB is generally considered normal. Information generated during VF testing is summarised using a series of metrics, which are reported on the output generated by the machine (see **Figure 1.7**). The HFA produces a greyscale image of the entire field where darker spots indicate less light perception. This greyscale image is useful for observing patterns of loss, and can be used to differentiate between conditions like COAG (where patches of the field will be progressively darker) and neurological disease (where entire quadrants of the field will appear black) (Yaqub, 2012). Additionally, the greyscale can be used by clinicians to explain glaucomatous loss to the patient and has been incorporated into patient education materials (Crabb, 2016, see **Figure 1.6**).

Figure 1.6: *Screenshots of the 'Glaucoma in Perspective' app (Glaucoma in Perspective UK on the App Store, 2019), which incorporates the HFA greyscale in order to demonstrate the subtle effects of COAG vision loss to patients (source: Crabb, 2016).*

The HFA subsequently produces a pattern deviation plot, used to calculate pattern standard deviation (PSD). The symbols on the bottom pattern deviation plot show point by point information which identifies if the value falls outside normative limits, / for example, a value of <1% demonstrates that less than 1% of the 'normal' population would display a value worse than the test eye. PSD is the standard deviation (SD) of the difference between the measured threshold and the threshold value in the normative database. PSD helps account for reduced vision due to cataract or uncorrected refractive error.

The total deviation plot shows the difference in sensitivity (in dB) between the patient and the 'normal' values from age-matched controls. A value of 0 indicates no deviation from the norm, whereas a minus value indicates that the light sensitivity in that location is poorer than expected. The total deviation plot is used to calculate the mean deviation (MD). The MD value represents the average variation across the field from a normative database, for example, an MD of -9.74dB for this patient represents a VF defect that is 9.74dB below that of age-matched controls. MD is perhaps the most important of the global indices produced by the HFA. MD in the better eye is strongly linked to visual function, QoL and limitations in activity at all stages of the COAG disease process (Crabb, Fitzke, & Hitchings, 2004; Alqudah, Mansberger, Gardiner, & Demirel, 2016; Saunders, Russell, & Kirwan, 2014) and is therefore considered to be a reliable indicator of disease severity in COAG patients. Older criterion for staging the severity of COAG, often categorise severity of COAG vision loss using a mixture of MD and PSD data but recent studies demonstrate that MD is a better predictor of vision-related QoL and visual function (Alqudah, Mansberger, Gardiner, & Demirel, 2016) and is also correlated to actual levels of RGC loss

(Medeiros, Zangwill, Bowd, Mansouri, & Weinreb, 2012). The studies in this thesis use MD as a surrogate measure of visual function.

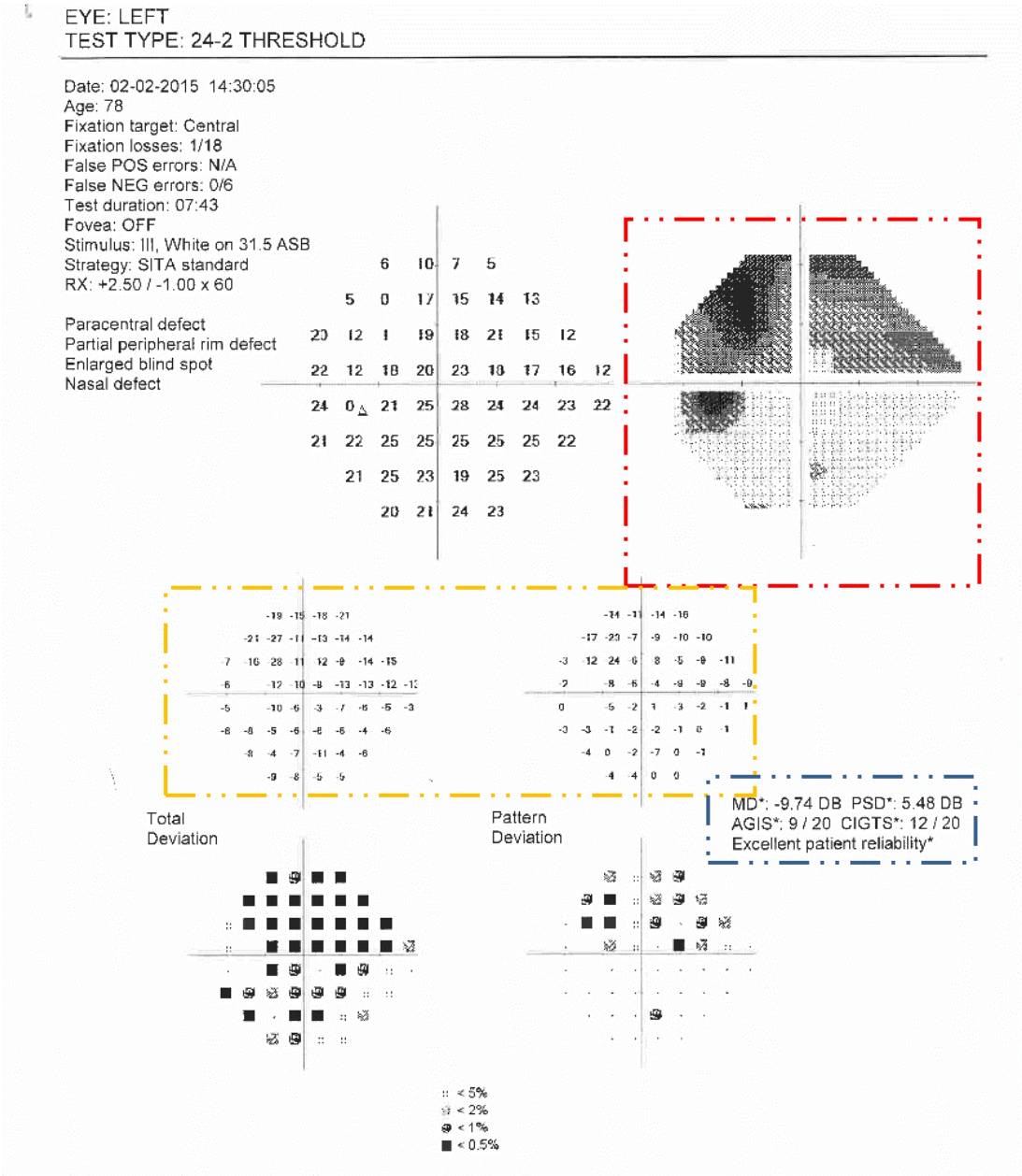

Figure 1.7*: An anonymised HFA output portraying a visual field from a left eye using the SITA standard 24-2 algorithm. The greyscale image is outlined in red. The total deviation and pattern deviation plots are outlined in yellow. The MD and PSD values are outlined in blue (source: author's own).*

1.2.5 Visual Acuity

Visual acuity (VA) is another commonly used method of assessing visual function in clinical practice (McClure et al, 2000). VA is an assessment of a person's ability to perceive detail at high contrast (black stimuli on a white background). Typically, to test VA, the patient is placed at a fixed distance of 6 metres from a chart and asked to read lines of letters which decrease in size. The smallest line which a person successfully reads is used to estimate their VA.

The most commonly used form of assessing VA is the Snellen chart (see **Figure 1.8**) which uses lines of letters which decrease in size. The patient is asked to sit 6 metres from the chart and the smallest line of letters they are able to read is used as the denominator in the VA. The numerator represents the distance that the patient is at. A VA of 6/6 represents that the patient can see, at 6 metres, what the average eye can see at 6 metres. The denominator increases as the patient's distance vision gets worse, so for example, a VA of 6/9 means that the patient can see, at 6 metres, what the average eye can see at 9 metres.

The Snellen VA chart has several important limitations, such as crowding effects due to the proximity of the letters at the top of the chart being wider than the narrower spacing between letters at the bottom of the chart. LogMAR VA is more commonly used in research, and is the method used in the studies within this thesis. LogMAR VA is commonly measured using charts (see **Figure 1.8**) developed as part of the Early Treatment Diabetic Retinopathy Study (ETDRS) (Ferris et al, 1982). ETDRS charts, in comparison to Snellen, have equal numbers of letters per line, equal steps and spacing between lines and equal spacing between letters across the chart.

Although many patients with glaucoma have preserved VA, those with advanced COAG or a scotoma in a more central location often have decreased VA(Asoaka, 2013). Decreases in VA in COAG are associated with loss of functionality, such as when reading signs or using the telephone (Richman, Lorenzana, & Lankaranian, 2010). Decreased VA in COAG has also been linked with worse psychological functioning, including a deterioration in positive self-image and an increase in symptoms of anxiety (Chan, et al., 2015).

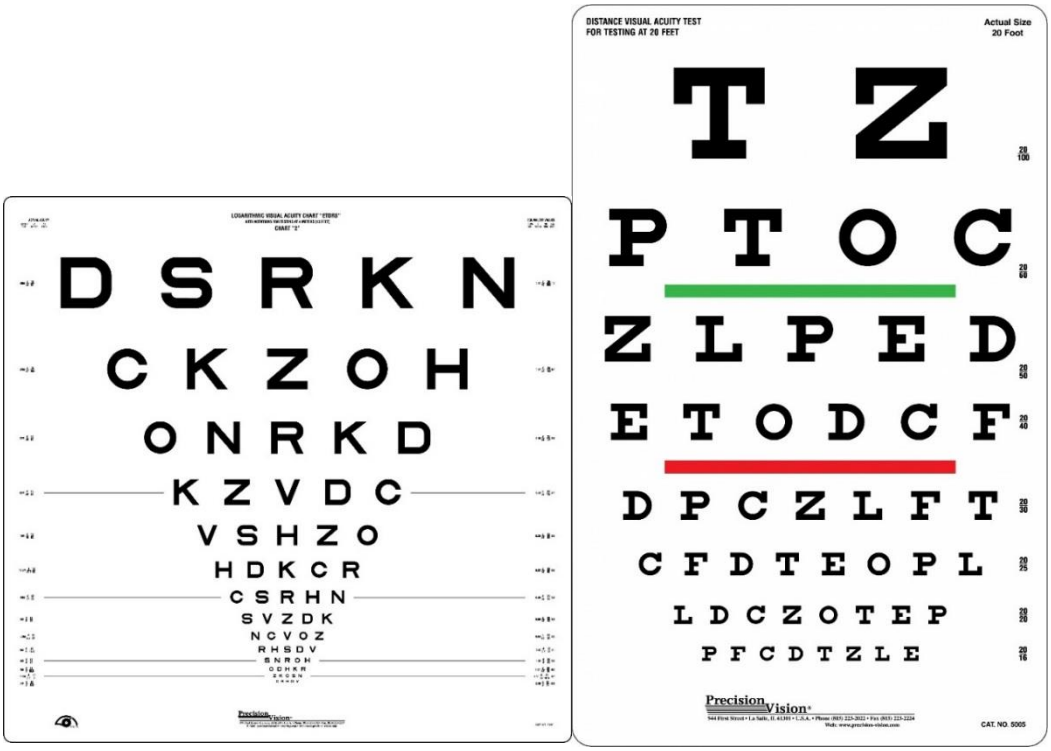

Figure 1.8: *Examples of an ETDRS chart (left) and a Snellen chart (right) used for measuring visual acuity. (source: left, https://www.precision-vision.com/product/4meteroriginalseriesetdrschart2/) and a Snellen chart (Source: right, https://www.precision-vision.com/product/snelleneyechartforvisualacuityandcolorvisiontest).*

1.3 Treating Glaucoma

As IOP is the only modifiable risk factor for COAG (Crabb, 2016), treatment focuses largely on decreasing IOP relative to baseline measurements. In COAG patients, reducing IOP by 20-40% generally reduces the average rate of VF loss over the lifetime of the patient by half (Weinreb & Khaw, 2004). Most patients will start with self-administered eye drops which are designed to lower IOP. If eye drops are ineffective or not appropriate, laser treatments to the trabecular meshwork or surgical intervention may be offered instead(National Institute for Health and Care Excellence, 2017).

1.3.1 Eye Drops

The first line therapy for COAG is generally self-administered topical drops. The most common drops for COAG are *prostaglandin analogue* drops, which are designed to increase the outflow of aqueous humour, thus lowering IOP. Commonly prescribed prostaglandin analogues include latanoprost, bimatoprost and travaprost. Prostaglandins are the preferred treatment by doctors due to their high efficacy and remarkably good safety profile (Sambhara & Aref, 2014). They are generally also the preferred method of treatment for patients as they are not accompanied by systemic side effects and need only be administered once daily (Li, Chen, Zhou, Wei, & Yao, 2006). Localised side effects of prostaglandin drops include hyperaemia (excess blood vessels in the eye), lash changes and colour change in the iris.

Beta-adrenergic agonists (beta-blockers), such as timolol, were once the first line therapy for COAG but are now often prescribed only as an adjunct to prostaglandins. Beta-blockers are generally administered twice daily and work

by decreasing the production of aqueous humour. Unlike prostaglandins, beta-blockers come with systemic side effects such as decreased heart rate, dizziness and headaches. Psychological symptomology, such as depression, confusion, decreased libido and alterations in mood are also associated with beta-blockers. Moreover, these psychological symptoms are less likely to be reported to a healthcare professional and less likely to be recognised as a medication side effect by the patient, leading to possible underreporting of prevalence (Stamper, Wigginton, & Higginbotham, 2002). Beta blockers may also cause redness or stinging locally when administered.

Alpha-2 adrenergic agonists, such as brimonidine, are generally administered twice daily but may sometimes be used three times a day. They attempt to lower the IOP through a combination of restricting aqueous production and promoting aqueous outflow. Alpha agonists are associated with many of the same systemic issues as beta-blockers, including fatigue, dizziness and a decreased heart rate. They may also be associated with worse localised symptoms, such as an increased risk of conjunctivitis and blepharitis (Sambhara & Aref, 2014).

Carbonic anhydrase inhibitors (CAIs) are a class of hypotensive drop, which work by decreasing the production of aqueous humour. Examples of topical CAIs are brinzolamide and dorzolamide but sometimes oral CAIs such as acetazolamide are used. CAIs are generally administered three times a day and are associated with several side effects such as eye irritation, lethargy and depression. CAIs have also been associated with several very serious side

effects, such as Stevens - Johnson syndrome (a rare and often fatal skin condition) and choroidal detachment (Sambhara & Aref, 2014).

Several newer classes of medicine such as *rho-kinase inhibitors* and fixed combination therapies have been trialled along with gene therapies and neuroprotective treatments, but these are infrequently used in clinical practice (Sambhara & Aref, 2014). The aim of these therapies is to reduce unwanted side effects in an effort to improve medication adherence. Estimates of non-adherence to COAG therapy vary from 5-80% (Olthoff, Schouten, van de Borne, & Webers, 2005) but it is generally thought that ~30-50% of patients do not take their medication as prescribed (Wolfram, Stahlberg, & Pfeiffer, 2019; Newman-Casey, et al., 2015). The reasons why COAG patients do not take their medications are multifactorial and complex with researchers suggesting that side effects, difficulties with schedule, difficulties instilling drops, forgetfulness and decreased self-efficacy play major roles in non-adherence (Wolfram, Stahlberg, & Pfeiffer, 2019; Newman-Casey, et al., 2015). The possible reasons for non-adherence and factors which may improve adherence are discussed in more detail later in **Chapter One**.

1.3.2 Laser Treatment

A number of laser treatment options are available for COAG patients, and these are becoming increasingly popular. *Selective laser trabeculoplasty (SLT)* involves a small laser which is directed at the trabecular meshwork. SLT is slightly preferable to the previously widespread *Argon laser trabeculoplasty (ALT)* due to its ability to target only cells in need of treatment (melanin pigment in the trabecular meshwork). The aim of both SLT and ALT is to increase aqueous

outflow, and both have been shown to be equally effective at lowering IOP at 1-year follow-up (Damji, et al., 2006). Due to its safety and long-term efficacy, as well as the low risk of side effects, SLT is becoming a popular treatment option for COAG. SLT benefits from often being a one-time intervention, which reduces the need for patients to be reliant on drop therapies. A large multi-centre randomised control trial (the LiGHT trial) has recently suggested that SLT should be offered as first line treatment for COAG, as it may be more cost effective in the long term and would lead to a reduction in the problem of non-adherence (Gazzard, et al., 2019). Although there is currently no evidence on long-term visual function from the LiGHT trial, studies in other neurological illnesses have argued that offering more aggressive measures earlier in the disease process may improve patients' functional outcomes (Batcheller & Baker, 2019).

1.3.3 Surgical Intervention

Surgical interventions for COAG are usually offered as the last line of treatment for COAG after laser and drop therapies have not achieved the desired reduction in IOP. They are occasionally offered to patients with severe glaucomatous damage on presentation as a form of emergency treatment (National Institute for Health and Care Excellence, 2017). The most common surgical intervention for COAG is a *trabeculectomy*, where a small incision is made in the trabecular meshwork to create an artificial drainage route for the aqueous humour. Trabeculectomy has a high long-term success rate, with around 80% of surgeries deemed successful at 5-year follow-up (Wilensky & Chen, 1996). However, as is the case with most incisive surgeries, trabeculectomy patients may suffer post-operative scarring which reduces the efficacy of the artificial

outflow system and may lead to the need for the surgery to be repeated. In order to avoid this complication, anti-scarring agents such as Mitomycin C and antivascular endothelial growth factor (anti-VEGF) may be used during or after surgery (Khaw, et al., 1992; Pozarowska & Pozarowski, 2016). However, it has been demonstrated that the repeated use of anti-VEGF therapies post-trabeculectomy may lead to an increase in IOP and the long-term implications of anti-VEGF therapies are yet to be established (Slabaugh & Salim, 2017). There are several *minimally invasive glaucoma surgeries (MIGS)* which attempt to perform the same role as a trabeculectomy using a less aggressive approach. These methods include trabecular micro-bypass stent insertion, canalicular scaffolding and gel and tube implantation. However, MIGS are relatively new and the long-term efficacy, cost effectiveness and impact on patient QoL are yet to be established (Kerr, Wang, & Barton, 2017).

1.4 Understanding Visual Disability in Glaucoma

In health psychological literature, the terms 'chronic disease' and 'chronic illness' have distinct definitions despite being used interchangeably in generic discussions (Martin, 2007). The term *chronic disease* refers to the **clinical aspects** of long-term disease, such as the aetiology (cause or set of causes), pathophysiology (the process of harm of the disease), signs, symptoms and treatment. This term may refer to communicable diseases such as HIV/AIDS and non-communicable diseases, such as diabetes or heart disease (Bernell & Howard, 2016). *Chronic illness*, on the other hand, refers to the **lived experience** of long-term disease. For example, the experience of taking a treatment daily and having routine appointments at the hospital. It is often the case that this lived experience is not recognised by healthcare systems, perhaps because lived experiences are harder to quantify than disease progression (Martin, 2007). This is generally the case in ophthalmic clinical practice, allying the healthcare system with an outdated medical model of disability. The patient is viewed only in terms of their medical status and the disability caused by that medical status is something a medical professional must treat and make normal (Brisenden, 1986). Due to this approach, a considerable portion of the assessment of the impact of COAG is based on 'visual disability. This is how clinical measurements such as VF translate to the performance of everyday tasks, which are guided by vision (Crabb, 2016).

1.4.1 Aspects of Visual Disability in Glaucoma

It is, of course, important to study the extent of physical impairment in COAG, and studies are numerous. COAG has been shown to affect many vision-related

activities of daily living, such as mobility, driving, searching for items, recognising faces, and reading.

Mobility

Mobility is often viewed as the most important aspect of visual disability since it is an essential component in maintaining an independent lifestyle. Reduction in mobility can have very serious consequences for patients, such as a reduced QoL and an increased reliance on others (Fenwick, et al., 2016). Mobility problems in COAG may manifest as slower walking speed, an increased incidence of bumping into things/problems with orientation or an increase in falls (Ramulu, 2009; Turano, Rubin, & Quigley, 1999). Mobility problems are more common in those who have bilateral VF loss.

Due to the increased mobility problems in COAG, a higher level of mental effort for patients to retain normal mobility is required, particularly as loss in the VF increases. It has been demonstrated that higher mental effort was exuded by COAG patients when they were faced with situations such as an area with high pedestrian traffic or a narrow hallway when compared with tasks such as climbing a staircase (Geruschat & Turano, 2007). This is supported by work from Goldberg et al. (2009) which showed that patients feel significantly more compromised when performing outdoor activities than activities within the home (Goldberg, et al., 2009). Perhaps for this reason, patients with COAG may be less likely to engage in physical activities, such as walking, especially patients with more severe VF loss (Ramulu, et al., 2012). This has implications for a patients overall health, as limitations in physical activity and a sedentary lifestyle have been linked to the development of conditions such as heart

disease, obesity and Type 2 diabetes (Carnethon, 2009; Hu, 2003). In other chronic disease, sedentary behaviour and limitations of physical activity are also associated with reductions in QoL (Hartman, et al., 2017).

Recognising objects and faces

There is a great deal of evidence that patients with COAG have difficulty with recognising objects in their environment such as faces, and particular objects when performing visual search tasks (Nelson, Aspinall, Papasouliotis, Worton, & O'Brien, 2003; Glen, Smith, & Crabb, 2013). Recognising faces and performing visual search tasks are done regularly, perhaps the most regular stimuli that a patient may encounter in their environment.

Patients with COAG are likely to find visual search tasks harder, and spend more time searching for an object. There is a strong relationship between the severity of VF loss and performance on visual search tasks (Altangerel, Spaeth, & Steinmann, 2006; Smith, Crabb, & Garway-Heath, 2011). There is also evidence that patients with worse vision fare worse when recognising faces (Glen, Crabb, Smith, Burton, & Garway-Heath, 2012), and they tend to make more frequent and larger eye movements (Glen, Smith, & Crabb, 2013). Difficulty recognising faces can cause distress in patients with COAG (Glen & Crabb, 2015) and has been linked to reductions in lifestyle and wellbeing in other eye disease (Tejeria, Harper, Artes, & Dickinson, 2002; Hassell, Lamoureux, & Keeffe, 2006; Mitchell & Bradley, 2006)

Driving

In addition to impaired face and object recognition and mobility problems, patients with COAG are likely to lose their driving license as their vision loss progresses. In fact, around a third of COAG patients with binocular VF loss would fail the fitness to drive test (Crabb, Fitzke, & Hitchings, 2004). Drivers with COAG who have not lost their license have been shown to be less safe (make more errors), despite rating themselves as safe as a control group (Wood, Black, Mallon, Thomas, & Owsley, 2016). Patients with COAG who are unable to drive have a worse vision-related Quality of Life, and this may be due to a loss of independence and a reliance on family members/friends in order to get around (Medeiros, et al., 2015). Assessments of Quality of Life in COAG are increasing in popularity but are still minimal in comparison to other eye diseases or other chronic disease in general (Glen, Crabb, & Garway-Heath, 2011).

1.4.2 Quality of Life in Glaucoma

Quality of Life (QoL) has been ill-defined in the literature, but the World Health Organisation (WHO) defines it as the difference between a person's goals, expectations, standards and concerns and their position in life in relation to the context and value system in which they live (Division of Mental Health and Prevention of Substance Abuse, 1997). Measures of QoL often fall short of this holistic definition and are generally designed to be specific to the illness or setting in which they will be administered. For example, QoL evaluations for patients with breast cancer often include mostly assessments of sexuality and

body image, whereas assessments of QoL in COAG focus more on how satisfied an individual is with their visual ability (Aaronson, 1988; Asaoka, et al., 2011)

Vision-specific or glaucoma-specific QoL measures are widely used in ophthalmic research and provide a good assessment of ocular symptoms and specific difficulties with vision-related tasks. An example of a widely used vision-specific QoL measure is the National Eye Institute visual functioning questionnaire (NEI VFQ-25). The NEI VFQ-25 is a useful measure for determining vision-related QoL as it encompasses questions about role limitations *(Are you limited in the kinds of things you can do because of your vision?)* and wellbeing *(I am often irritable because of my eyesight)* as well as assessing the patient's ability to complete vision-specific tasks *(because of your eyesight, how much difficulty do you have recognising people you know from across the room?).* Research has shown that the NEI VFQ-25 is a reliable measure for assessing change in vision-related QoL with worsening VF (Medeiros, et al., 2015).

However, it has been demonstrated that ophthalmologists in clinical practice frequently underestimate the extent to which vision loss impacts the patient's wellbeing (Brown, Brown, & Sharma, 2000). This may be due to an over-reliance on vision specific QoL measures which largely fail to account for emotional response to the illness and individual adaptation and coping strategies. Clinicians may also rely heavily on how clinical measurements such as VF relate to the patient's ability to perform certain daily activities. However, people with similar levels of vision loss and similar vision-related QoL may experience their COAG very differently, particularly when we consider the full

definition of QoL, which posits that the individuals 'position in life' as well as the context and value system which they are a part of must be considered. This is thought to be based on differing expectations of health and of life (Carr, Gibson, & Robinson, 2001).

Perhaps then it would be more appropriate to utilise a more generic measure of QoL in relation to COAG in order to capture non vision-related aspects of the illness. This may be useful in older patients where poor vision is unlikely to be the sole illness impacting QoL (Banerjee, 2015). One example of a generic QoL measure is the EQ-5D-3L, which is a commonly used general health PROM and is approved in the United Kingdom (UK) by the National Institute for Health and Care Excellence (NICE) 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. The scores are then translated into an index score ranging from 1 (perfect health state) to -0.624 (worst health state) using an existing scoring system (Devlin & Brooks, 2017). The EQ-5D-5L uses the same domains but is scored on a five point, rather than a three-point Likert scale. Index scores on the EQ-5D-5L range from a perfect health state of 1 to a worst health state of -0.594 (van Hout & Janssen, 2012). The EQ-5D may be a particularly useful instrument in assessing QoL in older people. In glaucoma, it is sensitive enough to distinguish between groups of patients with different disease severities and it has been demonstrated that index scores decrease with worsening disease. Decreased VA in glaucoma is also associated with EQ-5D score and this is particularly pronounced on the domains of mobility, self-care and anxiety/depression (Longworth, et al., 2014). In other neurological disease,

EQ-5D index scores have also been used to distinguish between patients with and without depression, falls and postural instability (Schrag, Selai, Jahanshahi, & Quinn, 2000). Using generic QoL measures means that although we may 'lose out' on some of the nuances which can be identified through vision specific QoL measures, we may be capturing a fuller picture of impairment on an individual level. The studies presented within this thesis therefore utilise the EQ-5D as a measure of QoL rather than vision-specific or glaucoma-specific instruments.

1.5 Cognitive, Emotional and Behavioural Response to Glaucoma

Quality of Life is one way to measure the experience of illness but it is unlikely that we can fully capture the experience of chronic illness without accounting for the cognitive, emotional and behavioural processes that take place in adapting to and maintaining ill health. These processes inform patient behaviour and individual goals, expectations, standards, and concerns, which may develop and change over course of the illness. The most meaningful way to capture these processes may be by investigating COAG through the lens of health psychological models of chronic illness.

1.5.1 Health Psychological Models of Chronic Illness

When considering which model to use as a theoretical research framework, it is important to consider the validity of the constructs (the extent to which they correspond to the real world), and the reliability of the model (the extent to which results from previous studies yield consistent results), as well as the comprehensiveness of the constructs themselves in terms of explaining health.

The Health Belief Model (HBM) consists of six interrelated constructs: perceived susceptibility, severity, benefits, barriers, cues to action and self-efficacy (a person's belief in their abilities to succeed in a specific situation or task (Bandura & Adams, 1977)). These constructs are used to predict the likelihood of health behaviours, such as uptake of screening programmes (Marmarà, Maramarà, & Hubbard, 2017). The HBM has been useful in attempting to explain certain health behaviours in COAG, such as medication

adherence (Newman-Casey, Weizer, Heisler, Lee, & Stein, 2013). In fact, the HBM was used as a theoretical framework in the creation of the Glaucoma Treatment Compliance and Assessment Tool (GTCAT). The GTCAT aims to measure perceived severity, perceived benefits, medication and control self-efficacy, perceived barriers and knowledge about glaucoma and has good internal reliability (Barker, Cook, Kahook, Kammer, & Mansberger, 2013). However, subsequent research with the GTCAT found that only some factors (white race, older age and being married) were actually predictive of adherence to medication (Barker, et al., 2015). suggesting limited usefulness of this model in explaining adaptation to COAG. One reason for this is that the HBM was proposed solely to explain the uptake of preventative health behaviours (Laranjo, 2016). Patients with COAG already *have* a diagnosis, so it can be argued that health behaviours in COAG are dictated more by maintenance of the condition, rather than being a preventative action.

Other models of health behaviour consider illness as a more dynamic experience, where there is a process of adaptation involving biological, psychological and societal factors. For example, the transactional model of stress and coping suggests that health behaviours are determined by a constant appraisal process, which is split into two systems (Hale, Treharne, & Kitas, 2007). The first is the primary appraisal system, responsible for processing the initial stress/threat level (for example, the diagnosis of disease). Furthermore, it determins whether the level is negative, neutral or positive, based on its perceived severity and cause and the person's motivation to act. (**Figure 1.9**). The secondary appraisal system involves a self-evaluation of coping abilities and resources for dealing with the stress/threat, such as the person's perceived

control over their emotions and their self-efficacy. The model suggests that coping behaviours are formed as a reaction to the perceived seriousness of the threat. These coping behaviours can be moderated by societal factors, such as social support, and emotional factors, such as emotional regulation. The coping behaviours in turn inform the outcomes experienced (the level of positive adaptation), including socioemotional outcomes, such as emotional wellbeing. The patient is then able to revise their goals based on these outcomes.

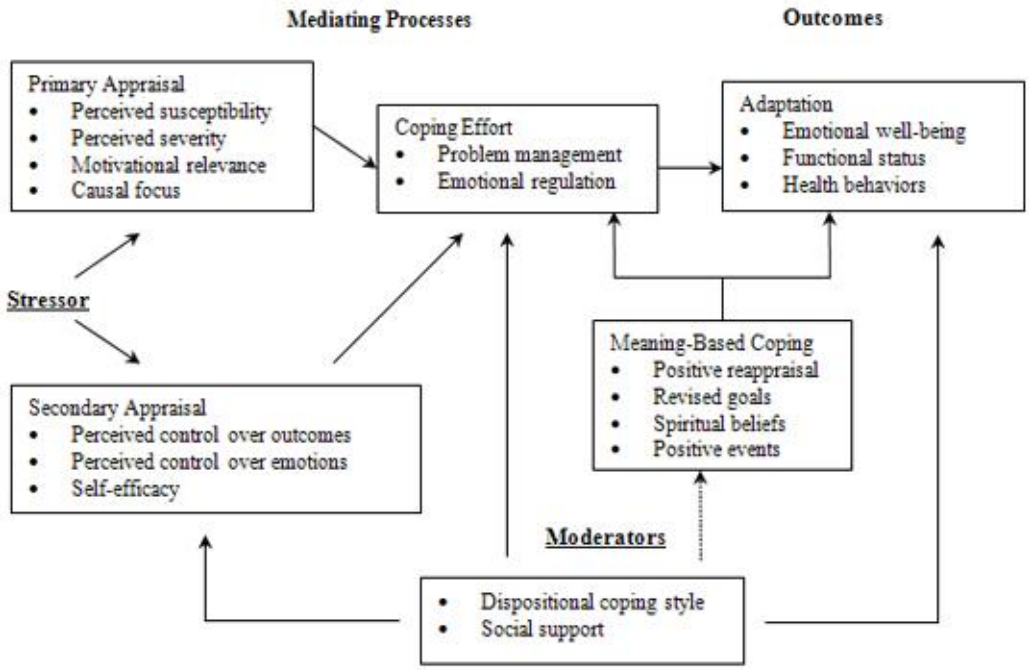

Figure 1.9: *The Transactional Model of Stress (source: http://www.med-upenn.edu/hbhe4/part3-ch10-theory-overview-shtml).*

The transactional model has the advantage of accounting for individual differences, such as a person's cultural and socioeconomic background but it does not sufficiently account for the development of affective responses to the illness, suggesting that emotional factors only play a mediating role in behaviours (Hale, Treharne, & Kitas, 2007).

The Common Sense Model of Illness Representations (CSM), in contrast, provides an explanation of how cognitive **and** emotional factors influence adaptation to chronic illness (Leventhal, Brissette, Leventhal, Cameron, & Leventhal, 2003; Leventhal, Meyer, Nerenz, & Rachman, 1980). The CSM suggests that patients use an appraisal system to constantly re-frame their illness representations and behaviours based on both internal feedback (e.g. emotional outcomes) and external feedback (e.g. health outcomes) (see **Figure 1.10**).

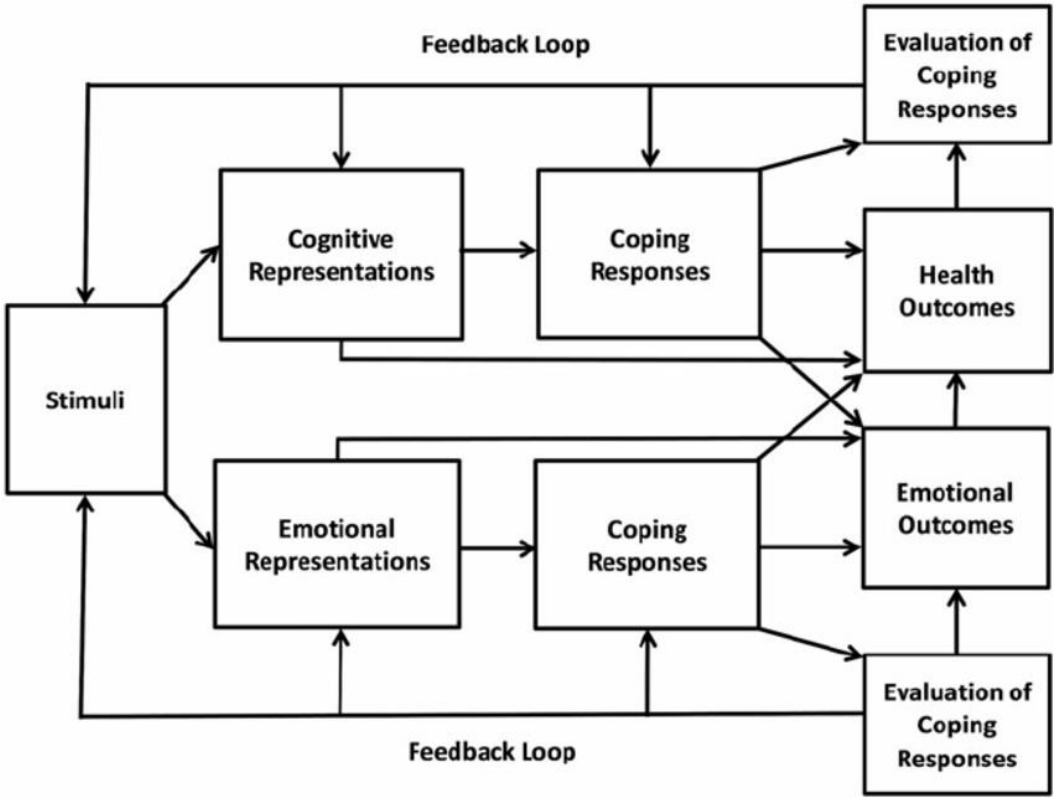

Figure 1.10: *The common-sense model of illness representations (Source: Heffernan, Coulson, Henshaw, & Barry, 2016).*

According to the CSM, individuals with a chronic illness form a set of cognitive representations surrounding their illness. These representations are formed along the domains of identity, consequences, cause, timeline and control/cure

(Leventhal, Brissette, Leventhal, Cameron, & Leventhal, 2003). In a parallel process, individuals also form emotional representations of their illness, which are affective reactions to their illness. These reactions may include depression, anxiety, fear or worry (Moss-Morris, et al., 2002). The cognitive and emotional representations that are formed dictate the coping mechanisms or strategies that are adopted by the patient. Coping strategies can be adaptive (seeking support, cognitive restructuring, problem-focused coping) or maladaptive (emotional numbing, escape, intrusive thoughts, rumination) (Thompson, et al., 2010). These coping strategies influence both clinical and emotional outcomes. The resulting outcomes lead to an individual's appraisal of the efficacy of their coping mechanisms, which in turn leads to a change in the cognitive and emotional representations held by the patient (Hagger & Orbell, 2003).

The aim of the following literature review is to provide a narrative account of studies related to the CSM to allow for a deeper understanding of the concepts discussed in the chapters of this thesis. For further systematic evaluations of CSM, please refer to the systematic reviews discussed within this section. Specifically, Weinman, Petrie, Moss-Morris, and Horne (1996), Moss-Morris, et al. (2002) and Broadbent, Petrie, and Main (2006) have systematically evaluated the CSM in terms of its validity and reliability.

1.5.2 Cognitive response

Cognitive representations of illness have been shown to be important to overall acceptance of the diagnosis and the development of adaptive coping strategies (Clare, Quinn, Jones, & Woods, 2016). Positive appraisal of illness representations has been linked to better long term outcomes, such as

improvements in self-care and patient engagement with healthcare services (Baker & Stern, 1993; Lorig & Holman, 2003). The opposite also appears to be true. negative framing of illness representations and poor adaptation can lead to worse outcomes in patients with chronic illness (Frostholm, et al., 2007). A recent review of 31 studies on illness representations found that the majority showed positive or favourable illness representations were associated with better health outcomes. It also found that negative or unfavourable representations were associated with worse outcomes, highlighting the reliability of the CSM domains in predicting outcomes across a range of health conditions (Sawyer, Harris, & Koening, 2019). Furthermore, research evidence has demonstrated consistent findings across five important interrelating dimensions.

Identity

Illness identity is the label or name given to an illness and the symptoms that are attributed to it. A strong illness identity can help the patient to legitimise the illness and make sense of it (Hale, Treharne, & Kitas, 2007). Identity becomes particularly important in diseases where the symptoms are not 'stable' because there is a chance that diverse symptoms which are unrelated to the illness may also be attributed to it (Meyer, Leventhal, & Gutmann, 1985). In a relatively asymptomatic disease like COAG, patients may attribute side effects of eye drop medications (such as redness) as side effects of their COAG (Nordmann, Auzanneau, Ricard, & Berdeaux, 2003). Patients who have variable symptoms may not engage with treatment opportunities as well as those who have a concrete illness identity (Hemphill, Stephens, Rook, Franks, & Salem, 2013). Recent qualitative investigations of illness representations in COAG patients

have revealed that those without strong illness identity are more likely to have poor medication adherence (McDonald, Ferguson, Hagger, Foss, & King, 2019).

Cause

Perception of the cause of an illness may play an important role in shaping a patient's engagement with healthcare professionals and their self-identity. It has been suggested that patients who feel their illness is a consequence of their own behaviours are less likely to report to healthcare professionals, but will show more effective self-management behaviours than those who attribute their illness to something external (Turnquist, Harvey, & Andersen, 1988). Research in patients with depression has also demonstrated that those who hold religious causal beliefs were less likely to engage with treatment effectively (Caplan & Whittemore, 2013). The causes of COAG are not well understood, and whilst high intraocular pressure provides an explanation for some patients, up to 50% of glaucoma is idiopathic (meaning it does not have an obvious cause) (Bell & O'Brien, 1997). In other disease where the origin is unclear, causal beliefs are important for determining outcomes. For example, idiopathic Parkinson's disease patients who held externalised causal beliefs (medication, other disease) perceived their illness to be more controllable than those who felt their disease was a random occurrence and displayed more adaptive coping strategies (Delaney, Simpson, & Leroi, 2011).

Timeline

Timeline beliefs, or the expected duration of the illness or its symptoms are key to determining illness behaviours and outcomes. Quantitative studies on illness representations have highlighted that patients who believe their illness to be an

acute condition, for example, are more likely to abandon their treatment programmes earlier than those who view their illness as chronic (Petrie & Weinman, 2006). The relationship between timeline beliefs and engagement with healthcare services is also mediated by the symptom timeline. Those with variable symptoms, despite viewing their illness as long-term, are more likely to disengage with treatment opportunities (Hemphill, Stephens, Rook, Franks, & Salem, 2013). It has been demonstrated that patients often have difficulties comprehending the long-term nature of chronic illness, leading to the development of maladaptive coping strategies, such as only believing they had the illness when exhibiting symptoms (Halm, Mora, & Leventhal, 2006). This has been coined the 'no symptoms, no asthma' belief, and may be particularly relevant for patients with COAG, where the condition is usually asymptomatic. This may explain that as many as 22-25% of patients already have advanced vision loss when they see an eye specialist for the first time (Crabb, Saunders, & Edwards, 2017). It is likely that the 'no symptoms, no asthma' belief is a maladaptive coping mechanism meant to shield the patient from negative emotional representations such as anxiety and depression, which can be associated with the belief that an illness will last a long time (Scharloo, et al., 1999; Llewellyn, McGurk, & Weinman, 2007).

Consequences

Consequence beliefs refer to the perceived impact of the disease, both physically and psychosocially. Previous qualitative research on illness representations in COAG has demonstrated that consequence beliefs may be thought of along these two axes (McDonald, Ferguson, Hagger, Foss, & King, 2019). Patients identified that practical (physical) consequences of COAG

included a reduced ability to go out/travel, see friends, tend to their garden, read or drive. These beliefs closely reflect what we know of the actual consequences of COAG (Crabb, 2016). Emotional (psychosocial) consequences that were identified included depression, concern/worry and loss of confidence, however, more than half of the patients in the study reported no emotional consequences from their COAG (McDonald, Ferguson, Hagger, Foss, & King, 2019). Fear of blindness is a well-documented consequential belief in COAG patients, with around 34% of newly diagnosed patients reporting a fear of blindness falling to 11% of patients at a five-year follow up (Janz, et al., 2007). This is further supported by qualitative evidence that suggests initial fear of blindness is replaced by a more reasoned perspective over time (Glen & Crabb, 2015). The aforementioned research does not look specifically at illness representations but does highlight the relative importance of understanding the patient's cognitive and emotional reaction to illness. The patient must view their illness as serious enough to warrant intervention or treatment, as those who have unfavourable consequence beliefs (e.g. the consequences of my illness are not serious) may not engage with treatment opportunities (Seamark, Blake, & Seamark, 2004; Mann, Ponieman, Leventhal, & Halm, 2009).

Control

Control beliefs have been identified by several studies as one of the strongest predictors of illness behaviour. Patients who feel that they can exert control over their illness more effectively are more likely to have a strong illness identity (Pierce, Kostova, & Dirks, 2003). Patients who hold unfavourable control beliefs, such as having no control over their illness and their illness being incurable tend to fare worst on dimensions of both physical and

psychological (Heijmans, 1998; Falvo, 2005). These patients are the ones that tend to employ more passive or maladaptive coping strategies. It has been suggested that patients with chronic illnesses may revert to a more dependent and passive state if they are unable to exert control as limitations in independence occur (Falvo, 2005). In addition, patients who do not feel that medication provides them with control over their illness are less likely to follow treatment regimens, especially if they also feel that their condition is not long term (Horne & Weinman, 2002; Rees, et al., 2014). This may be particularly important in COAG since it is incurable, and treatments may not halt disease progression entirely. There have been numerous studies which have indicated that beliefs about medicines, particularly that medicines will not help halt progression, are important for overall engagement with treatment regimens (Friedman, Hahn, & Gelb, 2008; Lacey, Cate, & Broadway, 2009; Tsai, McClure, Ramos, & Schlundt, 2003). One study demonstrated that improvements to control beliefs can be made through the use of individualised care planning for non-adherers in COAG patients (Gray, et al., 2012).

Research has demonstrated that illness representations may be closely linked with the long-term risk of disability. A study in osteoarthritis patients demonstrated that illness representations at baseline were associated with higher self-reported functional impairment at 2-year follow-up. This study also demonstrated that most domains of illness representation changed over the study period, including more favourable timeline and identity beliefs, but less favourable control beliefs (Damman, et al., 2018),

The advantage of using the CSM to investigate the cognitive response to illness is that most studies have used a version of the Illness Perception Questionnaire The Illness Perception Questionnaire (IPQ) (Weinman, Petrie, Moss-Morris, & Horne, 1996), the Revised Illness Perception Questionnaire (Moss-Morris, et al., 2002) and the Brief Illness Perception Questionnaire (Broadbent, Petrie, & Main, 2006) have been systematically evaluated in terms of their validity and reliability. It has been demonstrated that these measures have good predictive validity, the ability to predict scores on other measures and/or real life outcomes and good test-retest reliability, meaning that they yield consistent results across studies (Basu & Poole, 2016; Parfeni, Nistor, & Covic, 2013; Broadbent, Wilkes, & Koschwanez, 2015). There are a few studies which have considered illness representations in COAG as a predictor of medication adherence (Rees, Leong, Crowston, & Lamoureux, 2010; McDonald, Ferguson, Hagger, Foss, & King, 2019). Rees, Leong, Crowston and Lamoureux (2010), for example, found that scores on the Revised Illness Perception Questionnaire significantly predicted adherence to ocular hypotensive drugs in COAG patients. However, little is known about the formation of illness representations in COAG and how these may differ in patients in different stages of their illness. The measurement of cognitive illness representations in COAG using these tools is the main idea of the work presented in **Chapter Two** of this thesis.

1.5.3 Emotional response

The emotional response to chronic illness is often a complex process, and therefore may be commonly overlooked during routine clinical appointments (Turner & Kelly, 2000). However, it is important to consider because emotional responses influence coping strategies and subsequent clinical outcomes (Moss-

Morris, et al., 2002). It is widely acknowledged that a diagnosis of chronic illness has a profound impact on the patient's wellbeing, with a large number of patients developing anxiety and depression, amongst other negative emotions (Taylor & Aspinwall, 1996). The emotional response to chronic illness has been described along a spectrum of adaptive (expression and acknowledgement of emotions) and maladaptive (inhibition of emotions and avoidance) responses (de Ridder, Geenen, Kuijer, & van Middendorp, 2008). Previous research has demonstrated that the use of maladaptive coping strategies has been strongly linked to the latter. In patients with heart disease, the inhibition of emotions led to delays in health seeking behaviour (for example, going to the doctor when symptoms worsened), lower treatment adherence and poorer communication with healthcare providers (Wiebe & Korbel, 2003).

The acknowledgement of negative emotions may lead to the development of more adaptive coping mechanisms because this provides the opportunity to focus on threat, which in turn elicits action, a process known as problem-focused coping (Lutgendorf & Ullrich, 2002). It is thought that acknowledgement of negative emotions also contributes to *habituation*, whereby through writing, thinking or talking about the emotions, these emotions become a less intense and invasive experience (de Ridder, Geenen, Kuijer, & van Middendorp, 2008). In terms of illness behaviours, expression of emotions has been shown to contribute to lower levels of emotional distress, improvements to self-management behaviours and the creation of opportunities to engage with social support (Mann, et al., 2004; Austenfeld & Stanton, 2004).

A systematic literature review on older adults with visual impairments suggested that the emotional response to vision loss is often negative, particularly at the point of diagnosis (Nyman, Dibb, Victor, & Gosney, 2012). These findings are supported by evidence that COAG patients, in particular, have higher than normal levels of anxiety and depression (Mabuchi, et al., 2008). Some interesting qualitative observations about emotional representations at the point of diagnosis in COAG have been revealed in research involving interviews with patients (Hartmann & Rhee, 2006; Lacey, Cate, & Broadway, 2009; Odberg, Jakobsen, Hultgren, & Halseide, 2001). For example, patients describe being 'stunned' by their diagnosis or feeling that it was, 'an absolute blow' (Hartmann & Rhee, 2006; Lacey, Cate, & Broadway, 2009). Negative emotional responses in patients with poor vision have been shown to be associated with maladaptive coping responses, such as withdrawal from society or cessation of activities (Burmedi, Becker, Heyl, Wahl, & Himmselsbach, 2009; Glen & Crabb, 2015). However, COAG patients may also employ problem-focused coping strategies to deal with the potential emotional impact of their impairment, such as adjusting lighting or moving their heads in order to cope with their vision loss (Glen & Crabb, 2015).

There is evidence that patients with sight loss may not always receive appropriate support to address or express the emotions associated with their condition (Gillespie-Gallery, Subramanian, & Conway, 2013). This could be associated with the perceived cost associated with provision of what is termed Eye Clinic Liaison Officers (ECLOs). ECLOs play a key role in ensuring that newly diagnosed patients understand their diagnosis and are provided with the appropriate emotional and practical support. They are also able to provide

ongoing support with emotional wellbeing and can act as an advocate for the patient should they need to access social care provisions. It is estimated that 43% of ophthalmology services in England have no accredited ECLO service in place (RNIB, 2020).

However, face to face support with emotional responses may not be necessary, as there is evidence that other methods such as the internet and telephone may also provide an effective method of expressing and receiving support for negative emotions (Brown, et al., 1999). This idea is explored further in **Chapter Three.**

1.5.4 Behavioural response

As it has been previously demonstrated, behavioural responses to chronic illness are influenced by the cognitive and emotional representations that a patient forms and holds about their illness. Behavioural responses are also a very strong predictor of clinical outcomes in chronic illness (Heijmans, 1998). In short, behavioural responses to chronic illness, much like the representations that form them, can be adaptive or maladaptive.

Adaptive behavioural responses include searching for information about the illness, cognitive restructuring, engaging with social support and healthcare opportunities, and problem-focused coping strategies. Maladaptive responses include escapism, emotional numbing, intrusive thoughts, illicit substance use and rumination (Thompson, et al., 2010).

One of the biggest criticisms of the CSM is that it does not explicitly account for the influence of self-efficacy on health behaviour. There is a great deal of evidence that behavioural responses to chronic illness are mediated by self-

efficacy. Self-efficacy refers to a person's perceived ability that they will be able to succeed in a specific situation or task (Bandura & Adams, 1977). In patients with chronic pain, perceived self-efficacy predicted the formation of adaptive coping behaviours, and this effect occurred independently of cognitive ideas about the consequences of the coping behaviours (Jensen, Turner, & Romano, 1991). Higher self-reported self-efficacy scores were indicative of increased communication with caregivers, more involvement in treatment planning (partnership with clinicians), better self-advocacy and increased medication adherence in patients with chronic kidney disease (Curtin , et al., 2008). Self-efficacy has also been linked to increased diet control, exercise and symptom monitoring in patients with Type 2 diabetes (Sarkar, Fisher, & Schillinger, 2006). There is evidence that this relationship is bi-directional, patients who engage in self-management interventions also see improvements in self-efficacy (Lorig, Sobel, Ritter, Laurent, & Hobbs, 2001). However, more recent studies have demonstrated that cognitive representations of illness are strongly related to self-efficacy beliefs (Zelber-Sagi, et al., 2017). Being aware of this interaction is important, because it implies that enabling the patient to have the tools to succeed is imperative for successful adaptation to chronic illness.

1.6 Enabling the Patient in Glaucoma

1.6.1 Self-management

Self-management programmes based on encouraging appraisal and adaption of behaviours have been tested in patients with chronic illness, generally with good levels of success. Self-management refers to the process of the patient managing their own illness related behaviours (for example, through symptom monitoring) in order to maintain day-to-day functional status and lessen the impact of disease (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002). Evidence from randomised-control trials of self-management programmes suggests that teaching patients appropriate self-management skills leads to better outcomes, such as less hospital visits and a reduction in costs for healthcare providers (Bodenheimer, Lorig, & Holman, 2002). A study in COAG patients found that the development of effective medication self-management behaviours led to improvements in vision-related QoL (Wu, Xi, Xia, Lu, & Guo, 2014). Further evidence from studies in the developing world suggests that behaviour change interventions that rely on self-management techniques, support patients with cardiovascular disease to engage with their own healthcare. Patients are informed of risk factors for disease progression, thereby informing their consequence illness beliefs (Piette, et al., 2015). However, deciphering the exact components of self-management interventions has proven to be tricky.

A review of 223 studies on self-management interventions found no consistent format for interventions (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002). Common formats included interventions for drug management

(medication adherence), symptom management (including symptom monitoring), lifestyle management, and anger, stress and depression management. Training interventions included decision making, goal setting, managing uncertainty, assertiveness training, communication with doctors, clinical decision making, accessing support (asking for help) and educational training (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002). An interesting finding from this review was that there was little difference in effectiveness between interventions that were led by healthcare professionals and interventions that were patient-led (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002). This may mean that a patient-led self-management intervention may be a feasible, cost-effective option which could improve outcomes, particularly emotional outcomes, in COAG patients. This idea is explored as part of a self-monitoring exercise piloted in **Chapter Three**.

Another interesting note is that the review did not include any studies on self-management interventions for people with visual impairment, but this is simply because it was published before any real attempt was made to investigate self-management behaviours in these populations. Since that time, many papers have been published which have investigated the use of self-management interventions in patients with visual impairment (Newman-Casey, Weizer, Heisler, Lee, & Stein, 2013; Brody, et al., 2002). A randomised control trial with patients with age-related macular degeneration demonstrated that a self-management intervention containing cognitive and behavioural components led to significant improvements in mood, emotional distress and self-efficacy scores over a 6-week period (Brody, et al., 2002). A review of studies of educational self-management interventions for improving medication

adherence for patients with glaucoma found that the most effective interventions combined cognitive training surrounding barriers to adherence with educational training on the condition (Newman-Casey, Weizer, Heisler, Lee, & Stein, 2013).

1.6.2 Education

Education is an important component of self-management interventions in glaucoma, but in terms of its ability to enable the patient, it must be discussed in its own right. It is widely acknowledged that educational background is one of the key demographic factors which determines the cognitive response to illness, and subsequent engagement with healthcare services and health behaviours (Feinstein, Sabates, Anderson, Sorhaindo, & Hammond, 2006). Condition specific education delivered by a healthcare provider can have a positive impact on illness representations, particularly in the formation of a concrete illness identity and on consequence and control beliefs (Peterson-Sweeney, et al., 2007).

However, it has been demonstrated that over half of patients now use the internet as an educational tool and this may have important implications (Rainie & Fox, 2000). In COAG specifically, a number of online patient information resources depict the condition as a 'black tunnel' effect (**Figure 1.11**).

Figure 1.11: *An image depicting glaucomatous vision loss (Source: The London Eye Hospital: http://www.londoneyehospital.com/conditions/glaucoma/)*

However, research has challenged the traditional perception of glaucomatous VF loss as a 'black tunnel' and discovered that patients did not see their glaucoma as a tunnel effect at all, but rather as missing or blurred patches in their vision (Crabb, Smith, Glen, Burton, & Garway-Heath, 2013) (**Figure 1.12**). This misinformation could have huge implications because patients who do not associate their own vision with the image of a 'black tunnel' may be less likely to seek help from eye care professionals and may struggle with forming a concrete illness identity. It has been demonstrated in other conditions that patients who view their symptoms as 'atypical' when compared to societal beliefs about a condition presented to healthcare services later in the disease process (Ramirez, et al., 1999; Macloed, Mitchell, Burgess, Macdonald, & Ramirez, 2009).

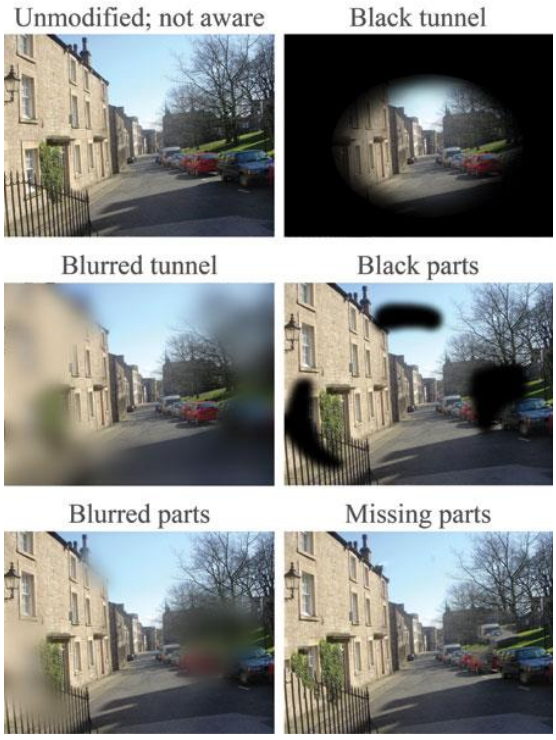

Figure 1.12: *Forced choice images used to assess perceived vision in COAG (Source: Crabb, Smith, Glen, Burton, & Garway-Heath, 2013).*

This problem is of course speculative, but it highlights the need for consistent post-diagnosis education for COAG patients. The study presented in **Chapter Two** therefore closely considers cognitive representations surrounding the understanding of COAG in this population.

1.6.3 Integrated care

Patient education and effective self-management are important tools for improving health outcomes, but they do not consider the wider context of the illness. Specifically, they may be ineffective tools for patients who are unable to monitor or assess their own illness behaviours and knowledge. There are many reasons why a patient may not be able to take full responsibility for their illness behaviours, but perhaps the most common is because of other health conditions becoming a barrier to effective management. Worldwide, around 65% of older adults (between the ages of 65 and 84) have more than one chronic illness (Banerjee, 2015) and the health consequences of this (termed *multimorbidity*) are not yet properly understood (Vogeli, et al., 2007). We do understand, however, that patients with diverse needs value having more input into clinical decision making (Mira, et al., 2013). Studies have therefore stressed the importance of what is termed *integrated care.* Integrated care models vary, but stakeholders may include the patient, the social support network (consisting primarily of informal caregivers (ICGs); friends and family members), healthcare providers and policy makers (Borgermans & Devroey, 2017).

Social support refers to actual or perceived support that the patient has with their condition (Reblin & Uchino, 2008). Social support given to patients to help with condition management by family members or friends is termed *informal caregiving*. There is evidence that adequate social support can benefit a patient in terms of both condition specific activities (taking medications appropriately) and general activities (self-care) (Sayera, Riegel, Pawlowski, Coyne, & Samaha, 2008). Further evidence shows that patients with latter stage chronic disease who have adequate social support are less likely to suffer from psychological symptomology (Applebaum, et al., 2014). However, studies in patients with heart failure have found that caregivers, like patients, go through a process of 'learning to cope' with the disease that relies on knowledge and the possible consequences, which are subject to the same problems as cognitive representations in patients (Kennedy, et al., 2017). This presents a problem because integrated care models rely on patients and their ICGs mastering a set of competencies that include making informed choices about care and medications and complying with agreed upon treatments (Borgermans & Devroey, 2017). Previous literature has highlighted the importance of ICGs providing emotional and informational support in patient/companion/physician consultations (*triadic consultations*). Specifically, ICGs may act as a memory aid, emotional support, elaborator, advocate, interpreter, company provider, or transcriber and play a key role in clinical decision making (Ellingson, 2002).

Little is known about the role of ICGs in COAG management. Studies have demonstrated that family members of COAG patients with multi morbidities act as monitors for medication adherence, and seek intervention when medication

adherence decreases (Read, et al., 2018). Other research with ICGs for patients with COAG has shown ICGs had minimal levels of engagement with the condition and expressed concerns about the lack of patient education and the development of poor coping mechanisms as a result (Shtein, Newman-Casey, Herndon, Coleman, & Lee, 2016; Waisbourd, et al., 2016). This may reflect the fact that ICGs who are not given the correct support have been shown to experience exhaustion, problems with their own wellbeing and reduced levels of self-esteem (Van den Heuvel, de Witte, Schure, Sanderman, & Meyboom-de Jong, 2001). Due to their importance to models of integrated care, studying the experiences of ICGs for patients with COAG and the possible impact of their role is imperative, and this is the main idea of the works presented in **Chapter Four** and **Chapter Five**.

1.7 Conclusion

This review of the literature has demonstrated that the studies on the CSM have yielded valid and reliable results. These results provide a fairly comprehensive overview of the experience of chronic illness in diseases like Type 2 diabetes and cancer. Chronic open-angle glaucoma is a complex disease. Often without obvious cause or symptoms, it requires significant lifestyle changes on the part of the patient. Whilst some evidence exists on the role of cognition and emotion in adaptation to COAG as a chronic illness, most studies in the area focus solely on improving medication adherence. Whilst this is an important goal in improving lives for COAG patients, there is a distinct lack of research on the day-to-day lives on COAG patients and their families.

1.8 Rationale and Aims of Thesis

In 2005, the UK Department of Health revealed that it would be shifting the focus of the NHS "*to move from a service that does things to and for its patients to one which is patient-led, where the service works with patients to support them with their health needs*". For this to become a reality, patients and their families need to be in a position where they are *aware* of their health needs and able to confidently communicate those needs to clinicians/practitioners.

The work in this thesis aims therefore to investigate the cognitive and emotional processes involved in adaptation to COAG as a chronic illness from the perspective of both the patient and their informal caregivers. Specifically, this thesis is organised as follows:

- **Chapter Two** investigates illness representations using a standardised instrument (the Brief Illness Perceptions Questionnaire – BIPQ). This chapter will describe cognitive representations of illness in two different populations (newly diagnosed patients with COAG/OHT and patients with a historical diagnosis of COAG/OHT between 2 and 5 years) to investigate whether illness representations are different between these groups. The primary hypothesis of this study was that COAG patients who are newly diagnosed would have more unfavourable (negative) illness representations. A secondary aim of this study was to investigate differences in illness representations between patients with COAG and patients with OHT.
- **Chapter Three** investigates the feasibility, in terms of self-advocacy and self-monitoring of behaviours, of a self-management intervention for

COAG patients. This intervention was delivered in the form of a web-based diary tool which encompassed both quantitative and qualitative data collection. The quantitative data were used to investigate improvements in positive health behaviours such as symptom monitoring. The qualitative data were used to elucidate information regarding the emotional response to the illness. This study specifically tested the hypothesis that a group of volunteer patients with an established diagnosis (more than 2 years) would be sufficiently motivated to regularly self-report on their symptoms.

- **Chapter Four** investigates the magnitude of informal caregiving (ICG) in COAG using a standardised instrument (Modified Caregiver Strain Index) and to place COAG on a spectrum of conditions to understand its impact on ICGs in the context of other well-studied disease. This data was collected using a postal survey of patients who self-identified an ICG. This study tested the hypothesis that measurable levels of caregiver strain exist in a sample of ICGs for patients with COAG.
- **Chapter Five** uses focus groups to collect qualitative data on experiences of ICG in COAG. In the first group, patients and ICGs were invited to talk about their experiences of providing and receiving informal care. The second group consisted of patients without an ICG, who were invited to talk about their attitudes toward informal care and experience of COAG. Interpretative phenomenological analysis was used to compare experiences of the two groups in order to answer the research question; '*What are the factors that form the experience of informal caregiving in COAG?*'

- **Chapter Six** provides a summary of the main findings of the work, discusses limitations of the findings, and provides suggestions for future research.

Chapter Two – Illness Representations in Patients Newly Diagnosed with Glaucoma and Ocular Hypertension

Formation and maintenance of cognitive illness representations is important for determining long-term outcomes in patients with chronic illnesses. Assessments of illness representations and how these relate to health behaviours have been investigated before in COAG. It has been demonstrated that illness representations, particularly beliefs about the effectiveness of treatment, are predictive of actual adherence to glaucoma medications (Rees, Leong, Crowston, & Lamoureux, 2010). To the author's knowledge, there is currently no research that has attempted to quantify differences in illness representations at multiple time points in the disease process in COAG and how these differences may relate to worsening VF. The work presented in this chapter aimed to quantify illness perceptions in patients with COAG and OHT at diagnosis and at between 2-5 years since diagnosis. A comparison of these groups would be used to investigate whether illness representations differ, and whether the presence of VF loss is important for formation and maintenance of illness representations. It also considers general health and personality as factors, which potentially mediate differences in illness representations between groups.

The work presented in this chapter formed a paper published in the British Journal of Ophthalmology (McDonald, et al., 2019); see list of supporting publications. The co-authors of this work are Trishal Boodhna (TB), Csilla

Ajtony (CA), Paula Turnbull (PT), Rupert Bourne (RB) and David Crabb (DC). TB gained ethical approval. Help with recruitment came from TB, CA, PT and RB. Data were collated and analysed by Leanne McDonald (LM). The paper was written by LM, reviewed by DC and approved by all co-authors. The work presented in this chapter has also been presented as a poster presentation at the Association for Research in Vision and Ophthalmology meeting (Seattle, WA, USA, 2016), as a poster presentation at the European Glaucoma Society congress (Prague, CZ, 2016), as an oral presentation at the United Kingdom and Éire Glaucoma Society Meeting (Cheltenham, UK, 2016) and as an oral presentation at the British Congress of Optometry and Vision Science meeting (Plymouth, UK, 2017); see list of supporting publications.

2.1 Introduction

Illness representations are feelings or beliefs that influence a person's psychological response to their illness. These representations are, for example, associated with clinical outcomes, coping behaviours and adherence to treatment (Petrie, Jago, & Devcich, 2007; Chen, Tsai, & Chou, 2011). A substantial body of research on illness representations in chronic disease exists but studies in people with chronic open-angle glaucoma (COAG) and ocular hypertension (OHT) are uncommon (Rees, Leong, Crowston, & Lamoureux, 2010; Friedman, Hahn, & Gelb, 2008; Saw, Gazzard, & Friedman , 2003; Gray, et al., 2012).

Interesting observations about negative illness representations at the point of diagnosis have been revealed in patients with COAG (Hartmann & Rhee, 2006; Lacey, Cate, & Broadway, 2009). Some of this negativity is likely attributed to the fear of going blind (Jampel, et al., 2007; Janz, et al., 2001). Indeed, it has been shown that simply giving a diagnosis of COAG negatively affects measures of QoL (Jampel, et al., 2007; Odberg, Jakobsen, Hultgren, & Halseide, 2001). Interviews with patients with COAG reveal initial feelings of fear were replaced by a more reasoned perspective over time (Glen & Crabb, 2015); this seems reasonable given most treated patients will not suffer significant visual impairment in their lifetime (Saunders, Russell, & Kirwan, 2014; King, Azuara-Blanco, & Tuulonen, 2013). 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 COAG/OHT. A better understanding of this idea has clinically relevant implications about how 'diagnosis' of COAG/OHT should be handled and communicated.

One way to examine illness representations in COAG would be to ask patients directly and subject the responses to qualitative analysis (Lacey, Cate, & Broadway, 2009; Glen & Crabb, 2015; McDonald, Ferguson, Hagger, Foss, & King, 2019). Alternatively, patient reported outcome measures (PROMs) have been used to quantify illness representations in chronic conditions (Broadbent, Wilkes, & Koschwanez, 2015; Pesut, Bursuc, & Bulajic, 2014). Results from PROMs measuring illness representations have been linked to self-management behaviours, including attendence to follow-up appointments (Frostholm, et al., 2007). They have also shown to be related to a decline in social and physical functioning in a variety of conditions (Scharloo, et al., 1998; French, Cooper, & Weinman, 2006). A widely used and validated PROM instrument is the Brief Illness Perception Questionnaire (BIPQ)) (Broadbent, Petrie, & Main, 2006; Broadbent, Wilkes, & Koschwanez, 2015). Therefore, in order to assess a patients' illness representations, this study uses the BIPQ in conjunction with other PROMs of QoL and personality, along with a measure of patients' visual function.

The aim is to quantify illness representations in patients with COAG and OHT. The primary hypothesis of the study centres on newly diagnosed COAG and OHT patients having worse illness representations when compared to a group of patients who have lived with a diagnosis for more than two years.

2.2 Materials and Methods

This was 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 (Hinchingbrooke Hospital)). Newly diagnosed patients were introduced to the study at the end of the clinic visit where they were first diagnosed. For the purpose of simplicity, in the methods and results, these participants are referred to 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. These participants will be referred to 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 were anonymised and stored securely.

Study participants (> 40 years) had a diagnosis of COAG 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 COAG 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 COAG) to provide a representative cross section of patients. In other words, this allows for an age related and disease severity-related analysis. In the COAG groups, mean deviation (MD) in the least affected eye (the eye with the better MD) was used as a measure for disease severity (Saunders, Russell, & Kirwan, 2014). 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. Previous research suggests that the biggest changes to illness representations happen within the first two years of diagnosis, with negative emotional representations decreasing and illness coherence (understanding of the condition) increasing over that period (Lawson, Bundy, Belcher, & Harvey, 2013) A 5 year follow up period is then used for most longitudinal studies (Bijsterbosch, et al., 2009; de Rooij, et al., 2018). This study therefore considered patients between two- and five-years post diagnosis as having sufficient diagnosis history.

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 representations, general health, and personality type.

[1] Brief Illness Perception Questionnaire (BIPQ) - The BIPQ has been widely used to investigate illness representations in chronic illness (Broadbent, Wilkes, & Koschwanez, 2015; Pesut, Bursuc, & Bulajic, 2014; Broadbent, Petrie, & Main, 2006). Eight items are scored on a 0-to-10 scale, with 80 representing

the most negative illness representations. 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] EQ-5D– The EQ-5D-3L (EuroQol, 1990) is a commonly used general health-related QoL PROM and is approved in the United Kingdom (UK) by NICE as a general health measure for health economic analysis. The five items are scored accordingly: 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 (Devlin & Brooks, 2017).

[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) (Denollet, 2000). This instrument has seven items for negative affect and social inhibition, respectively. Each item is scored from 0 (least distressed) to 4 (most distressed).

Data analysis

The primary hypothesis was that cases would have a 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 (Broadbent, Petrie, & Main, 2006) gave a

suggested minimum sample size of 28 participants per group, which was the recruitment target.

Mean BIPQ score, age, best eye MD (BEMD), worse eye MD (WEMD), EQ-5D index score and DS14 were compared between cases and controls for the COAG and OHT groups. All individual data distributions were checked for normality. Univariate association between overall BIPQ against age, DS14 and EQ-5D index score was explored to assess covariance in the data.

An average score from each of the eight separate BIPQ items was also compared between cases and controls for the COAG and OHT groups using Multivariate Analysis of Covariance (MANCOVA); this corrects for any covariance from age, DS14 and EQ-5D 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 method described in previous research (Broadbent, Petrie, & Main, 2006). 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).

2.3 Results

The recruitment period for the study ran from January to November 2015. Questionnaires were completed by 124 participants, with eight excluded due to incomplete consent or unreliable VFs. The 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. The majority of participants (77%) self-reported that they were married or in a committed relationship.

COAG cases and controls were well related for age, BEMD, WEMD, and DS14 (**Table 2.1**). COAG controls had slightly worse average self-reported general health (EQ-5D) when compared to COAG cases (p=0.03). For OHT study groups the cases and controls were similar for age, EQ-5D and DS14.

Table 2.1 *– Mean (standard deviation) age, BEMD, WEMD, EQ-5D index and DS14 for each of the four study groups.*

	N	Age (y)	BEMD (dB)	WEMD (dB)	EQ-5D Index	DS14
COAG						
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**

The mean (standard deviation; SD) BIPQ score for COAG cases and COAG 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 representations 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 representations in this sample of people with COAG 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 EQ-5D (r=0.28, p=0.04), suggesting illness representations 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 2.2**). Statistically significant differences between groups on each item are reported from a comparison of adjusted means using a MANCOVA adjusted for DS14 and EQ-5D scores. In this analysis, statistically significant effects occurred in four items in COAG 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 'how long do you think your COAG will last?'. In comparison to newly diagnosed patients, people with COAG for >2 years better understood

their condition would last for a 'long time'. In comparison to newly diagnosed patients, people with COAG 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 COAG 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 2.2**) are noteworthy. For example, most participants understood their COAG/ OHT is going to last forever but a number did not. There was also a wide response to the question about control over COAG/ OHT, particularly for the OHT patients, revealing that many participants felt they did not have good control over their condition.

Table 2.2 – *MANCOVA results for differences between COAG 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 EQ-5D index scores. The p values marked with * denote a significance level of <0.01*

	COAG	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	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)	

understanding)						
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 COAG/OHT. Where participants (n=46) gave more than one cause only the first written response in the list was considered. The summary of the coded responses, stratified by cases and controls, are shown in **Table 2.3**. 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 (Coleman & Miglior, 2008). 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. The decision to analyse only first written response was based on the majority (73%) of second and third responses being "incorrect". The majority of second and third ranked causes were related to lifestyle factors (reading and TV, work environment) or other ocular or non-ocular disease (thyroid, migraines, diabetes, contact lenses, eye strain).

Table 2.3 – *Frequency of first written response by group to Q9 of the BIPQ (Broadbent, Petrie, & Main, 2006), '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%)

2.4 Discussion

This cross-sectional study used an established method of measuring illness representations (Broadbent, Petrie, & Main, 2006) to investigate average differences between newly diagnosed COAG/OHT patients (cases) and those with a diagnosis of more than two years. Results indicate no difference in overall illness representations 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 COAG/OHT does not precipitate a sudden development of negative illness representations when compared to other people who have lived with the condition for more than two years.

These findings represent new knowledge about illness representations in people with COAG/OHT. For example, results suggest diagnosis may not be as distressing as previous studies have indicated (Hartmann & Rhee, 2006; Lacey, Cate, & Broadway, 2009; Odberg, Jakobsen, Hultgren, & Halseide, 2001). Overall illness representations of participants were, for example, similar to those from other studies that have used BIPQ to assess heart palpitations (Broadbent, Wilkes, & Koschwanez, 2015) or pre-treatment pulmonary tuberculosis (Pesut, Bursuc, & Bulajic, 2014). In contrast, scores were lower on average than those found in people with diabetes (Broadbent, Petrie, & Main, 2006). These comparisons allow illness representations of COAG/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. For example, the present study used an independent groups design with matching, rather than following the same patients longitudinally. This presents an issue because the CSM

stresses that illness representations are formed on an individual level (Petrie, Jago, & Devcich, 2007). Whilst the present study provides good evidence that changes may occur, a longitudinal cohort study should be conducted in order to fully investigate the dynamic nature of illness representations in COAG.

Secondary analysis of individual BIPQ items, when corrected for patient's level of distressed personality (measured by DS14) and self-reported QoL (measured by EQ-5D) revealed interesting results. Unsurprisingly, newly diagnosed COAG patients held less realistic beliefs about their condition compared to people who had the diagnosis >2 years. Moreover, newly diagnosed COAG 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, COAG 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 (Petrie & Weinman, 2006; Hemphill, Stephens, Rook, Franks, & Salem, 2013). This suggests more should be done, at the point of diagnosis, to make sure patients are aware that their condition is permanent.

COAG cases reported they understood their condition better than those with a diagnosis of more than two years. This particular result was unexpected. Perhaps though, this might be explained by the very recent information

received about COAG during diagnosis. This is contrary to previous findings, which demonstrated that understanding of COAG was poor in the majority of patients (McDonald, Ferguson, Hagger, Foss, & King, 2019). In addition, patients' causal beliefs were also interesting; the majority of participants could identify a "true" risk factor for COAG and OHT (Coleman & Miglior, 2008) but many also held untrue causal beliefs. Many patients correctly understood COAG/OHT to be largely idiopathic and this warrants further study because work in other chronic conditions has shown this perception can influence long-term outcomes (Delaney, Simpson, & Leroi, 2011).

Beliefs about control over COAG/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 wellbeing and adherence to treatment in other chronic disease (Heijmans, 1998; Falvo, 2005; Ross, Walker, & MacLoed, 2004). 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 (Horne & Weinman, 2002). This finding reinforces the importance of communicating the important message about necessity of adhering to a life-long treatment to people with COAG/OHT, as it has been demonstrated that this can improve medication adherence (Gray, et al., 2012).

A notable finding is the similarity in illness representations between patients with ocular hypertension (OHT) and manifest glaucoma (COAG). Long-term prognosis for OHT patients is relatively good, with only a small proportion

developing COAG (Gordon, Beiser, & Brandt, 2002). These findings indicate OHT patients may need different information at diagnosis to help improve representations surrounding the consequences of their illness. This will also ensure patients understand how their diagnosis is different to a diagnosis of manifest glaucoma.

This 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 COAG/OHT. Moreover, the analysis took account of self-reported general health (EQ-5D) and distressed personality as confounders of response to BIPQ. Furthermore, sample sizes were large enough to support a finding of no differences in average BIPQ across the 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 this 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 also found racial differences in illness representations (Kim, Pavlish, & Evangelista, 2012) but there is evidence that general education level may not be associated with illness representations (Hsiao, Chang, & Chen, 2012). The results of the current study may have been subject to volunteer bias too; data was not collected on people who chose not to participate or who did

not return questionnaire packs. Moreover, information about patients' co-morbidities was not recorded and many elderly people have more than one chronic illness (Barnett, et al., 2012). Still this limitation was mediated by using a measure of self-reported general health-related QoL (EQ-5D) (Van Nispen, de Boer, & Hoeijmakers, 2009) and the analyses were corrected for this. There is a small chance that patients in the study had untreated cataract, which may not have been noted on the EPR and that this may have acted as a confounding variable. Future research could consider using a combination of pattern standard deviation and MD as a surrogate for visual function. This study used MD alone, as research has demonstrated that MD is most closely allied with real world QoL (Alqudah, Mansberger, Gardiner, & Demirel, 2016). Furthermore, patients with between a two- and five-year diagnosis history were included as controls in this study. Some studies have suggested that the most significant changes in illness representations happen in the first two years of diagnosis (Lawson, Bundy, Belcher, & Harvey, 2013). However, it is possible that there are differences between illness representations in patients with a two-year diagnosis history and, for example, patients who were four years post diagnosis, which would not be reflected in the analysis. In future research, it may be worthwhile to measure time since diagnosis as a linear variable in order to investigate changes in COAG illness representations more thoroughly.

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 (Schwartz & Quigley, 2008). 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, looking 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 representations in the same individuals over time.

To conclude, overall illness representations 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 COAG patients do not realise their condition permanent. Remarkably, people with a diagnosis of OHT had similar negative illness representations 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 representations held by OHT patients may highlight the need for better communication about the nature of their diagnosis and prognosis.

Chapter Three – Feasibility Study of a Symptom Self-Monitoring Intervention for Glaucoma

Understanding the dynamic nature of illness representations in glaucoma, and the factors associated with these informs clinicians about the potential barriers and facilitators to a patient's positive illness behaviours. However, the experience of chronic illness extends beyond measurements of illness representations. For example, previous studies on treatment adherence interventions in glaucoma have found that factors such as patient enablement and knowledge of glaucoma also play a key role in the success of intervention programmes (Richardson, et al., 2013; Newman-Casey, et al., 2015). One way to better enable patients might be to encourage self-monitoring of illness symptoms. Encouraging patients to self-monitor their symptoms may have benefits for both emotional and functional outcomes in chronic illness (Eastwood, Travis, Morgenstern, & Donaho, 2007; Basch, et al., 2016).

The work presented in this chapter aimed to explore how people with glaucoma *might* self-monitor visual symptoms and the emotional response to illness, with the aim of enabling them to become more engaged in their 'glaucoma journey'. This was investigated through the use of a set of symptom monitoring questions, and a diary approach whereby patients could record information about their daily experiences with glaucoma. This work also considers personality traits as a possible mediator of self-monitoring behaviour.

The work presented in this chapter formed a paper published in the Journal of Ophthalmology (McDonald, Glen, Taylor, & Crabb, 2016); see list of supporting

publications. The co-authors of this work are Fiona Glen (FG), Deanna Taylor (DT) and David Crabb (DC). Ethical approval was gained by FG. The self-monitoring diary tool was designed by FG and DC. Recruitment was performed by FG and the International Glaucoma Association. Data was collated and analysed by Leanne McDonald (LM). The paper was written by LM, reviewed by DC and approved by all co-authors. The work presented in this chapter has also been presented as a poster presentation at the Association for Research in Vision and Ophthalmology meeting (Seattle, WA, USA, 2016) and as an oral presentation at the School of Human and Social Sciences Doctoral Research conference (London, UK, 2016); see list of supporting publications.

3.1 Introduction

Whilst the clinical and biological mechanisms of glaucoma are well explored, the impact of glaucoma on an individual's wellbeing has been relatively understudied (Glen & Crabb, 2015; Glen, Crabb, & Garway-Heath, 2011). Patient reported outcome measures (PROMs) estimate perceived health status, functional status or health-related QoL. PROMs, often administered as questionnaires, have been used to assess the effect of glaucoma on QoL in research studies for some time (Parrish, et al., 1997; Nelson, Aspinall, Papasouliotis, Worton, & O'Brien, 2003) PROMs are starting to be used as end-points in clinical trials of treatments for glaucoma (Vickerstaff, Ambler, Bunce, Xing, & Gazzard, 2015). Such use of PROMs is a positive step because they directly assess impact of symptoms of disease on a patient, certainly as they perceive it themselves. To date PROMS are not used in regular clinical management of patients with glaucoma. Yet the benefits for this idea have been speculated upon and PROMS are being increasingly used in the clinical management of other conditions (Devlin & Appleby, 2010; Timmins, 2008).

In the United Kingdom (UK) there are more than one million hospital visits a year for glaucoma (Wright & Diamond, 2014); clinicians likely have inadequate time and resources to cope with these visits. Moreover, opportunities for patients to discuss their psychological wellbeing or the functional impact of their glaucoma at these visits, are uncommon. This is a pity because better information between clinic visits and time for patient/clinician interaction may lead to better glaucoma management (Mirzaei, et al., 2013). At the same time,

patients spend only a few hours a year in the eye clinic having their glaucoma monitored, but they spend more than 5000 waking hours each year engaged in everything else (Asch, Muller, & Volpp, 2012). This statistic suggests that there should be time for patients to potentially self-monitor their symptoms in between clinic visits. Self-monitoring approaches have proved effective in other chronic conditions such as type 2 diabetes (Farmer, Gibson, Tarassenko, & Neil, 2005); these methods might be useful for people with glaucoma and this is the main idea explored in this study.

Self-monitoring, in this case, is defined as a method where individuals keep a record of their behaviour (e.g. feelings during event), in connection with efforts to change/control behaviours (American Psychological Association, 2020). In previous literature, self-monitoring of chronic illness in cardiac and cancer patients, (both physical symptoms and emotional impact) has shown improvements in self-reported functional status and slower declines in QoL (Basch, et al., 2016; Eastwood, Travis, Morgenstern, & Donaho, 2007). Self-monitoring of illness has also been explored in AMD patients through the use of diaries, and the findings indicate that these methods may provide a useful way of capturing the emotional response to illness (Stanford, Waterman, Russell, & Harper, 2009). In the long term, the opportunity to reflect on their emotional representations may benefit patients in terms of QoL, leading to the development of more adaptive coping mechanisms. It is thought that acknowledgement of negative emotions contributes to *habituation*, whereby through writing, thinking or talking about the emotions, these emotions become a less intense and invasive experience (de Ridder, Geenen, Kuijer, & van Middendorp, 2008). This is likely because bringing emotional representations

to the forefront, leads to appraisal of coping strategies (Moss-Morris, et al., 2002). Therefore, increased engagement with the condition may lead to better overall wellbeing.

Personality may be linked to a patient's engagement with their condition, and their ability to monitor their own emotional representations. For example, higher trait levels of extraversion have been linked to an increased uptake of intervention and self-management programmes (Furnham, 1989). Other investigations of the so-called "big five" personality traits (Openness to experience, Conscientiousness, Extraversion, Agreeableness, Neuroticism) revealed that higher levels of extraversion and emotional stability are significantly related to uptake of self-monitoring (Barrick, Parks, & Mount, 2005; Kring, Smith, & Neale, 1994).

This work explores how people with glaucoma might self-monitor visual symptoms and emotional responses with the aim of enabling them to become more engaged in their 'glaucoma journey'. It also examines how self-monitoring may be influenced by personality traits. This study specifically tests the hypothesis that a group of volunteer patients will be sufficiently motivated to regularly self-report on their physical symptoms and emotional state; examining the feasibility of this using a web-based diary tool.

3.2 Materials and Methods

Participants responded to an invitation to take part in the study from a patient based charitable organisation (IGA - http://www.glaucoma-association.com). The study was a prospective mixed methods feasibility study, which took place over eight weeks in 2015.

Ten participants were recruited from different glaucoma clinics across England; all had a clinical diagnosis of chronic open-angle glaucoma (COAG) and the mean (SD) time since diagnosis for the participants was 18 (9) years. A minimum sample size of ten participants has been suggested for any thematic analysis study to produce sufficiently trustworthy results (Sim, Saunders, Waterfield, & Kingstone, 2018). Due to the pilot nature of the study, a sample of 10 participants was deemed sufficient to investigate the feasibility of the web-based tool. Participants were asked to respond if they had glaucoma alone and no other ocular disease other than prior uncomplicated cataract surgery.

The study was approved by a Research and Ethics Committee (City, University of London, School of Health Sciences) and adhered to the tenets of the Declaration of Helsinki. Data was anonymised and stored in a secure location. All participants gave their informed written consent prior to taking part.

Pre-testing

Participants were asked to attend a face-to-face baseline visit at the university to complete a series of pre-test measures to confirm their eligibility for the study, before being introduced to the web-based diary tool. Visits lasted approximately 2 hours and participants were provided with refreshments. A Mini Mental State Examination (MMSE) was used to exclude people with any

measureable cognitive impairment. Studies suggest that a cut-off score of 27 (26 or below) out of 30 detects cognitive impairment in 90% of cases (O'Bryant, et al., 2008). None of the study participants scored below this cut-off. Participants then underwent an examination of their vision by a qualified optometrist (DJT). This examination included refraction, measurement of contrast sensitivity (CS), visual acuity (VA) and a slit lamp examination on both eyes. An examination of the visual field (VF) confirmed that all participants had measureable VF loss in at least one eye. VFs were measured (Swedish Interactive Threshold Algorithm Standard 24-2) using a Humphrey Field Analyser (HFA) [Carl Zeiss Meditec, Dublin, CA]. The best sensitivity values at each location of the monocular VF's were merged to construct an integrated visual field (IVF) (Asaoka, et al., 2011). This technique is useful because it provides a simple visual representation of a patient's binocular vision.

Participants completed the EuroQol 5-Dimensions (EQ-5D) questionnaire and the Ten Item Personality Inventory (TIPI) at the start of the study in a face-to-face interview.

[1] EQ-5D - EQ-5D (EuroQol, 1990) is a five-item measure, designed to measure general health. The 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. The individual 1-digit item scores are combined into a 5-digit number, which describes health state. For example, a score of 12112 indicates a participant has some problems with self-care and anxiety but no other perceived problems.

[2] Ten-Item Personality Inventory - TIPI (Gosling, Rentfrow, & Swann, 2003) estimates levels of extraversion, agreeableness, conscientiousness, emotional stability and openness to experience. The scale consists of 10 items, each scored on a 7-point Likert scale from 1 (disagree strongly) to 7 (agree strongly). Two items exist for each of the five traits, and scores for each trait are a mean of the two items (1-7).

Web-based monitoring and diary tool

Participants were introduced to the web platform at their face-to-face baseline visit and provided with a unique login. The web platform was designed to be user friendly and easy to navigate (**Figure 3.1**). Participants were provided with a guidebook, which gave web tool instructions.

Participants were asked to complete a set of bespoke 'symptom monitoring' questions every three days. Participants were asked how much driving, walking, searching for objects, using a computer, watching television and eating and drinking were affected by glaucoma. These questions were scored on a 5-point Likert scale from 'not at all' to 'very much'. A summary measure at each time point was generated (5 (no symptoms) and 45 (maximum symptoms)).

Participants were sent automatic email prompts every three days as a reminder to complete the questions. Participants were also invited to complete a written diary, documenting any aspect of their glaucoma that they felt would be helpful to record. They could do this by typing directly into the web-based tool as frequently as they wanted to and could even upload photographs. This would be recorded by time and date. Again, they were prompted by an automatic email every three days.

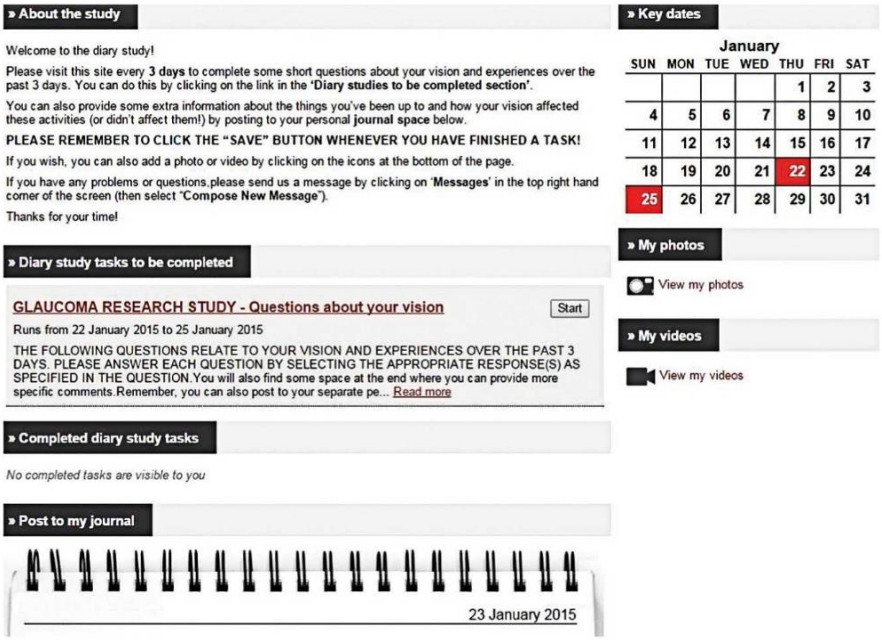

Figure 3.1 - *A screenshot of the web-based diary tool used by the participants. The page is split into "to be completed" and "completed" tasks.*

Study Evaluation

Participants were asked to complete a series of questions about the usefulness of the exercise at the end of the eight-week study period;

1) How valuable did you find keeping a diary about your vision and experiences? 1 "not valuable" – 5 "very valuable"
2) To what extent has your view of your glaucoma and/or vision changed since the beginning of the study? "I am more aware of my vision loss since beginning the study", "Since beginning the study, I notice the effects of my vision loss more during my everyday activities", "I have found new ways of dealing with my glaucoma since the beginning of the study", "I have been better at remembering to take my drops since beginning the study".

3) Did you ever keep a journal or write down information about your vision and glaucoma care before the study? Yes/no
4) Will you ever keep a journal or write down information about your vision and glaucoma care after the study? Yes/no
5) What methods would you consider using to help keep a diary or log of your vision and glaucoma care? Website, computer documents, paper journal, smartphone app, other, none.

Analysis

The composite symptom scores for each time point were used to plot change in symptom awareness over the course of the study. Individual personality traits for each participant were compared to mean scores on the TIPI in a cross-sectional sample of the UK population (Holmes, 2010). Frequency of words written was used as a proxy for level of diary usage. Univariate association between diary use and scores on personality traits were explored using Spearman's rho. The results from the evaluation questionnaire were assessed with simple summary statistics.

The information from the online diary tool was analysed using thematic analysis (Braun & Clarke, 2006). The lead researcher (LM) collated raw diary responses from each participant and read through the responses several times for familiarity. The next step involved coding any units (sentence, paragraph) that related to the patient's emotional response to their illness. Each diary was coded separately, and then related sections of text were grouped into themes. Themes were only generated where at least two participants talked about a subject in their diaries; data from single participants was excluded from the

analysis. The analysis was then shared with DC to ensure that there were no major errors in judgement. Data analysis stopped when no further information was discovered in the diaries.

3.3 Results and Findings

Participants (50% male) had a median age of 70 (interquartile range [IQR] 66 to 76) years. Participants were from different regions of the UK and were educated to a minimum of high school level. All participants were married or living with a long-term partner.

A summary of patient's vision and baseline data is given in **Table 3.1**. HFA mean deviation (MD) in the better eye (BEMD) was used as a proxy measure for glaucoma disease severity. BEMD ranged from early to advanced, with median (IQR) BEMD -9.1 (-6.1, -13.4) dB. Four participants had BEMD worse than -12dB, and this level is sometimes described as advanced VF loss (Saunders, Russell, & Crabb, 2012).

Table 3.1 - *A summary of patient's vision and baseline data.*

	Years since diagnosis	Binocular visual acuity (LogMAR)	Binocular contrast sensitivity	Best eye HFA mean deviation (dB)	EQ-5D general health
M1	21	-0.2	1.95	-13.7	11111
M2	5	0	1.5	-7.9	11111
M3	26	-0.02	1.65	-5.5	11211
M4	23	-0.1	0.9	-17.4	21111
M6	25	0	1.95	-11.4	11111
F1	29	-0.1	1.2	-9.2	11111
F2	11	-0.1	1.35	-19.4	11211
F3	6	0	1.95	-2.2	11121
F4	15	0.1	1.35	-13.6	21211
F5	15	0	1.35	-9.0	11221

Symptom monitoring

The completion rate of the symptom monitoring questions **(**96% over the eight-week period) was remarkably good. Composite symptom scores (from 5-45)

for each time point were used to plot individual change in symptom awareness over the study period. Loess curves were fitted to the data points in order to illustrate any 'trend' in symptom awareness during the study period (Jacoby, 2000). These trends are purely illustrative given the short follow-up period. Participants were remarkably engaged with the diary entry tool. The median (IQR) number of diary words recorded per patient was 1858 (703, 4094) over the 8-week period.

Six participants reported higher levels of extraversion and/or openness to experience than the UK sample. Emotional stability was weakly correlated (rho=0.39; p=0.05) with the uptake of the diary exercise (number of words written in the diary exercise). There were no other statistically significant associations, but the sample size was very small.

Thematic analysis

Four main themes emerged from the thematic analysis at a semantic (explicit) level.

Frustration

Participants often reported a feeling of frustration regarding their impaired ability to complete tasks because of their vision:

'It is very difficult to describe what it's like except that I know that my vision is not the same as it was a few years ago, it's not good and it's not right' **(F2).**

Some participants felt frustration at themselves, describing that they should be able to complete certain tasks such as reading:

'As reading has become less pleasant, the piles of items waiting to be read tend to build up. Must try harder!' **(F3).**

'Not driving - wouldn't feel safe. Extremely difficult to read & shop. Getting very bad tempered & frustrated after almost 2 weeks of this.' **(F5).**

Anxiety and cessation of activities

Some participants reported that they had stopped performing certain activities due to fears associated with their vision loss. Some of the instances of avoidance behaviour were pre-planned:

'I find it difficult to see in the dark these days as I struggle where there is very little contrast. I have stopped driving at night but live in an urban area that is reasonably well served by public transport.' **(F2).**

There were also instances that appeared to be triggered by situational anxiety:

'During the night I started worrying about coping with trains and planes on my own and where I'd be able to find somewhere to rest up during Monday, as the only flight was very early. I felt so awful by Sunday morning that I decided I'd have to stay at home. So much for thinking I am back to normal…' **(F3).**

Social support

Participants in this sample discussed social support networks mostly in a positive light but sometimes reported feeling guilty at having to rely on a partner for social support and feared becoming a burden:

'[Name omitted] drove me there but didn't come on the walk herself – I always feel a bit guilty about this...' **(M6).**

'*I don't like to rely on my partner for lifts, but he often obliges. I will go out on foot with my trusty torch where necessary*' **(F2).**

Participants reported strong social support networks, including partners, friends and emphasised the importance of professional support groups:

'IGA AGM was very much worthwhile attending. Loop system was working well so I could hear clearly. Particularly interested in all the research going on, DVLA [Driver and Vehicle Licensing Agency] aspect most relevant' **(F4).**

Social support networks seemed to consist of different people for different participants; one reported a lot of activity involving friends, but some only talked about partners. Regardless of whom the network consisted of, participants spoke about the importance of their social support network understanding their glaucoma related issues:

'I wouldn't have recognized him if he hadn't spoken – that sort of non-acknowledgement can probably seem rude to anyone who doesn't know about your glaucoma (I did apologize to him using the glaucoma excuse).' **(M2).**

Some also identified social activities as an important 'distraction' factor:

'I'm not one for staying in bed but would prefer to keep active. Not up to my usual standard but still enjoyed the session. Didn't have time to ponder on how I felt and how my eyes were affected.' **(M6).**

Clinician Trust

Participants described different aspects of their glaucoma care in their diary entries. Most participants indicated that they had high levels of trust and a helpful dialogue with at least some of their care team:

'Just glad my glaucoma was picked up when it was. If this is the sight I have 'for ever' whatever that means for me - then I am very grateful to have been looked after in the way I have been. ' **(F1).**

There were very few participants who reported negative aspects of care, although some participants reported concern regarding interactions with professionals during their glaucoma care, which led to mistrust:

'Opticians, new varifocals on order, titanium, bit pricey @ 640. But prefer to stick with local independent opticians. As one of larger chains, in my view, ""missed"" evidence of Glaucoma in its early stages when I complained that right eye vision through their new specs/lens provide was slightly inferior to left. This goes back some 8 years.' **(M2).**

Overall, the participants in this study reported having very positive relationships with their clinicians.

Evaluation of study

Overall, participants reported that they found the diary exercise valuable, with eight out of ten participants rating the exercise 'valuable' or 'very valuable'. One participant did not engage with the diary exercise and rated it not valuable at all. One participant rated the exercise neutral.

Interestingly, eight participants said they felt more aware of their vision loss and its effects since the beginning of the study. Only two of the ten participants

felt that the intervention improved their medication adherence. Three participants felt that they had developed new ways of dealing with their vision loss.

Four participants said that they were more likely to keep an independent diary about their vision after completing the eight-week diary exercise. From the options given in the evaluation questions (**Figure 3.2**), five participants said they were most likely to use a web based or computer-based diary tool.

Participants' experiences of the diary exercise were mostly positive. Participants generally felt that they received benefit from the diary exercise and that they would continue to benefit from using the process in the future:

'Thank you for asking me to take part in this research. No-one else knows the hassles I have mentioned, many others have bigger daily problems to cope with, so mine are trivial in comparison' **(F4).**

Although the majority of comments were positive, one participant reported negative feelings:

'I don't think my sight is any worse than it was a few weeks ago, only that I am more focused on it. I am not sure that this is a good thing because it makes me more aware of problems when I would normally just deal with them or ignore them' **(F2).**

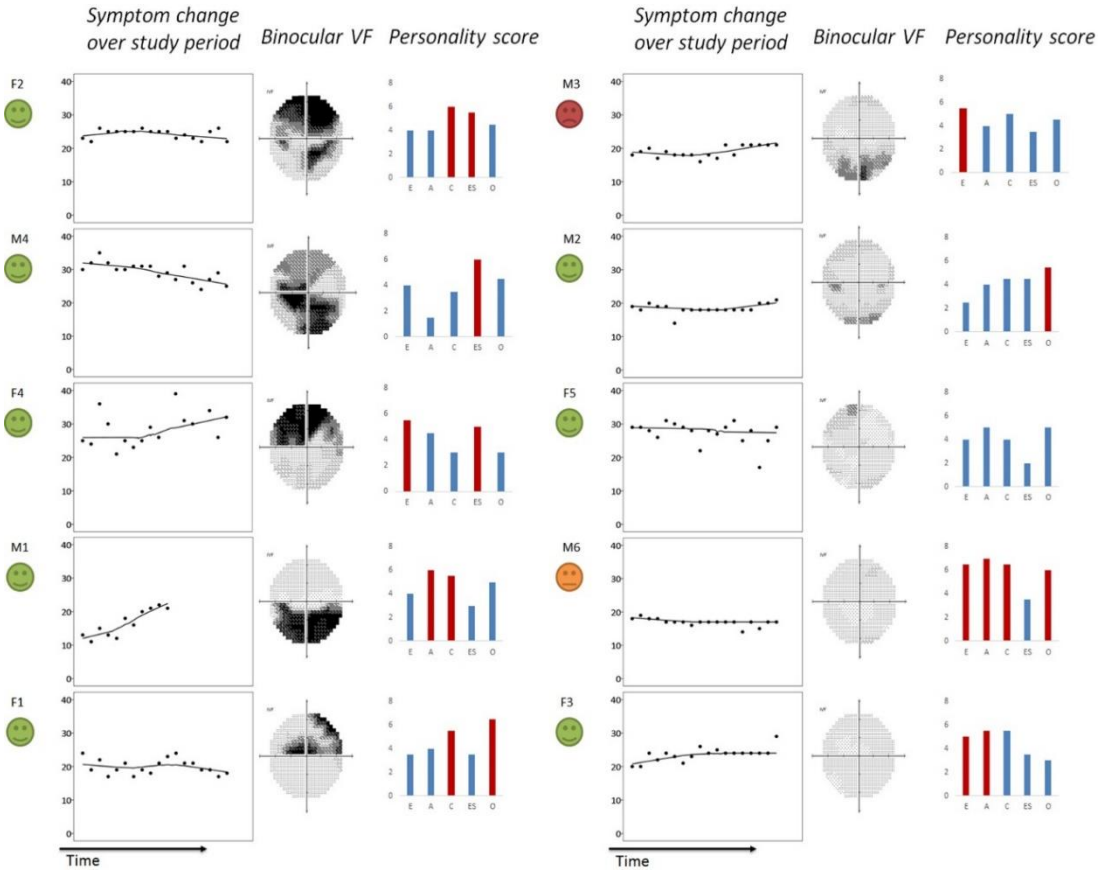

Figure 3.2 - *Shows results from 10 participants ordered according to the severity of binocular visual field loss. From left to right: face indicates self-response to review question about the value of the self-monitoring exercise; time series plot shows a composite visual symptom score recorded over a study period of 8 weeks. Binocular visual field is shown as grey scale of integrated visual field. Individual bar chart indicates response to Ten Item Personality Inventory (TIPI) questionnaire (E: extraversion, A: agreeableness, C: conscientiousness, ES: emotional stability, and O: openness). Red bars indicate that trait is significantly higher than a reference population. For example, volunteer M6 had four significant personality traits.*

3.4 Discussion

A group of self-selected volunteer patients, with a range of disease severity and personality types, adhered well to using a web-based diary tool to monitor their glaucoma symptoms. Participants were able to report their own symptoms with remarkable regularity yielding plots of how their symptoms were potentially changing over time. Most participants felt more aware of their vision loss after being in the exercise. Themes emerging from the qualitative synthesis of the diary entries were related to behavioural aspects that might be overlooked in typical patient-clinician consultations. This study speculates that aspects of a patient's emotional response to glaucoma (frustration/anxiety) could be flagged by an on-line monitoring tool and then assessed in clinical consultations.

An investigation of the feasibility of self-monitoring symptoms of COAG has not been done before. This study therefore represents new knowledge, as it has at least demonstrated how this might be feasible in groups of volunteer patients. Research into surveillance of glaucoma away from the clinic has, for example, focused on monitoring intraocular pressure and aids for improving adherence to treatment (Araci, Su, Quake, & Mandel, 2014; Mudie, et al., 2016; Boland, et al., 2014). Here it has been demonstrated that this approach might also be useful in recording information about wellbeing between clinic visits. Self-monitoring techniques have been shown to play a useful role in patient care in other chronic conditions (Farmer, Gibson, Tarassenko, & Neil, 2005; Eastwood, Travis, Morgenstern, & Donaho, 2007). The volunteers in this study were remarkably positive about the idea of self-monitoring. This may be related to the volunteer's personalities. For example, six

participants reported higher levels of extraversion and openness to experience, than a reference standard. Extraversion in particular has been linked to better uptake of self-monitoring interventions in the past (Furnham, 1989).

Several patients in the study reported feeling anxious about their glaucoma. This is interesting because a higher prevalence of anxiety disorders has been demonstrated in other chronic illness (Brenes, 2003). Research has suggested that age and vision in the better eye are significant predictors for anxiety in glaucoma patients (Mabuchi, et al., 2012). Patients also reported frustration at losing their everyday abilities. Evidence from other eye diseases has found links between loss of functional abilities and frustration (Lamoureux, Hassell, & Keefe, 2004). Negative feelings likely have an impact on patient's self-efficacy and, if they are not identified and addressed, patients may be more likely to develop depression (Horowitz, Reinhardt, & Kennedy, 2005). An online monitoring tool may allow some patients to articulate these anxieties and this could be clinically useful in the management of glaucoma.

The results from this study hint at important clinical applications and these can be speculated on briefly now. Evidence suggests that PROM's such as the ones used in this study, as well as self-monitoring exercises, provide important clinical information about patients and act as part of a collaborative management plan in chronic illness (von Korff, Gruman, Schaefer, Curry, & Wagner, 1997). Many patients may not get an opportunity to discuss their condition during clinic appointments (Friedman, Hahn, & Gelb, 2008; Friedman, et al., 2009). A diary tool may allow patients to use reflective thinking in order to pinpoint difficulties with their

condition. For example, one participant in the study reported that she felt her problems were 'trivial' compared to others and chose not to share them. Plotting self-reported symptoms, using an appropriate tool, could have the same motivational behavioural effect as measuring daily steps as a measure of exercise (Middelweerd, Mollee, van der Wal, Brug, & te Velde, 2014). This might be useful in terms of engagement and adherence with treatment. Patients in this study also discussed the importance of their social support network as a protective factor for their wellbeing. Previous research has demonstrated that adequate social support can benefit a patient in terms of both condition specific activities (taking medications appropriately) and general activities (self-care) (Sayera, Riegel, Pawlowski, Coyne, & Samaha, 2008). There is further evidence that patients with latter stage chronic disease who have adequate social support are less likely to suffer from psychological symptomology (Applebaum, et al., 2014). The impact of glaucoma on social support networks may therefore provide an interesting avenue for future research.

Participants in this study provided a substantial amount of written information about their psychological wellbeing, which may not previously have been shared with clinicians. Patients may be less likely to disclose psychological distress with clinicians due to fear of stigmatisation or involvement of mental health services (Stablein, Hall, Pervis, & Anthony, 2015; Dew, Morgan, Dowell, Bushnell, & Collings, 2007). Interestingly some evidence suggest patients are more likely to disclose information of a sensitive nature if they are able to do so using technologically advanced methods, such as through a web-based tool (Kobak, 2001; Lucas, Gratch,

King, & Morency, 2014). An online tool may therefore yield more information about a patient's psychological wellbeing when compared to a hospital consultation and this should be investigated further.

One patient concluded that a constant focus on monitoring symptoms led to negative feelings and experiences. This is very noteworthy. Previous research has suggested that private self-focus and rumination is associated with depression and generalised anxiety in some people (Mor & Winquist, 2002). However, other studies have suggested that expression of negative emotions can contribute to habituation (de Ridder, Geenen, Kuijer, & van Middendorp, 2008). This observation would be important to consider in the development of the idea of self-monitoring symptoms in COAG. Moreover, the diary tool was making patients more aware of problems with their vision and this has significant implications that need to be considered in a future study. It would be interesting to integrate a positive psychology exercise (for example, an exercise where participants are asked to record positive aspects of their day, such as the 'three good things' technique) into future iterations of any self-monitoring exercise (Action for Happiness, 2016). Research has demonstrated that positive psychology exercises enhance patient engagement with their condition and have been shown to improve life satisfaction (Wood, Froh, & Geraghty, 2010). It may be interesting to consider a traditional diary vs. a positive psychology tool alongside measures of adherence to treatment and QoL measures to investigate whether different types of emotional disclosure lead to different outcomes. Interestingly only two of the ten participants in this study felt that the intervention improved their medication adherence.

The experimental design of this study had several strengths. The web pages were well designed, and all data was safely and securely captured. The combined use of qualitative diary and symptom monitoring questions may also be a strength of the study. Of the ten participants, only one chose not to use the qualitative diary tool throughout the course of the study – however, this participant did complete the symptom monitoring questions. The current study used a multifaceted approach, which allowed participants to engage only with the parts of the exercise that they were comfortable with. This is in contrast to previous investigations of self-monitoring behaviour in COAG, where methods have solely focused on measuring medication adherence (Richardson, et al., 2013; Newman-Casey, Weizer, Heisler, Lee, & Stein, 2013). The benefits of the diary element of the exercise may be linked to the expression of emotional representations of illness, with literature suggesting that inhibition of emotions results in delays to health seeking behaviour (Wiebe & Korbel, 2003). However, there may be issues with using a diary tool in a busy clinic environment. It is unlikely that clinicians would have enough time to read through diary entries. Previous self-monitoring studies have investigated emotional wellbeing through the use of PROMs, where significant changes in scores are automatically communicated (via email) with nursing teams (Basch, et al., 2016). In this study, nurses frequently initiated clinical action in response to the email alerts. Future research should consider using PROMs, rather than written diaries, in order to measure emotional representations of illness. Changes in PROM scores could be communicated to specialist glaucoma nursing teams or ECLOs, who may have more time to respond to changes in wellbeing. This would allow for emotional

representations of illness to be measured using traditional psychometrics whilst not overwhelming stretched clinical services.

There are also several limitations to our study. The study sample was small, and the glaucoma profile of the patients was very varied; this prevents us from drawing real conclusion other than proving the practical feasibility of the approach. Volunteers were self-selected and motivated. Volunteers had good levels of education and were sufficiently engaged with their glaucoma because, for example, they belong to a patient organisation. It is hard to predict if adherence to the exercise would be so good in another population. There is also a lack of available research on the optimum frequency of self-monitoring. A systematic review of studies suggests that participants are generally satisfied with monitoring once a week, but that some felt that this was insufficient. Participants were generally not happy to monitor themselves daily either (Walsh, Golden, & Priebe, 2016). The current study asked participants to self-monitor their behaviour every three days, and this seemed to be an acceptable frequency. However, future research could investigate the frequency of symptom monitoring and its impact on engagement. Furthermore, due to the small sample size and feasibility approach of the study, it is difficult to form any conclusions about the validity or reliability of the web-based tool. One factor that improves the reliability of the results is the use of low-inference descriptors in the thematic analysis. Quoting participants verbatim increases the likelihood that the accounts presented are as representative as possible of the real-life experience. It is common practice in thematic analysis research to also attempt to capture latent themes (underlying ideas, patterns or assumptions) (Braun & Clarke, 2006). The

analysis for this study only considered semantic (explicitly stated) themes to improve the reliability of the information on emotional representations of participants.

In conclusion, volunteer patients, with a range of disease severity and personality types, adhered remarkably well to using a web-based diary tool to monitor their self-reported glaucoma symptoms. A web-based diary intervention for the self-monitoring of glaucoma may therefore be practical. Future work should examine the feasibility of this approach in larger groups of patients with broader methods of recruitment and examine if it can change behaviour or be clinically useful. The monitoring tool must be carefully designed in order to ensure participants are benefitting, and it is not increasing anxiety.

Chapter Four – Assessment of Informal Caregiver Burden in Glaucoma

As disability in glaucoma increases, so may the importance of the social support network in maintaining patient wellbeing. However, the experience of being what is deemed an *informal caregiver* can be a complex issue incorporating physical, psychological, financial and emotional changes (Burleson Sullivan & Miller, 2015). When these experiences are negative, it is termed caregiver strain (Peters, Jenkinson, Doll, Playford, & Fitzpatrick, 2013). Assessments of caregiver strain are important because informal caregivers have been shown to experience exhaustion, problems with wellbeing and reduced levels of self-esteem (Van den Heuvel, de Witte, Schure, Sanderman, & Meyboom-de Jong, 2001). There is also evidence that negative connotations with the role of an informal caregiver can impact long-term patient-caregiver relationships (Fingerman, Pitzer, Lefkowitz, Birditt, & Mroczek, 2008; Connidis & McMullin, 2002). Previous research involving interviews with informal caregivers providing care to patients with COAG has revealed that there are strains associated with this role (Shtein, Newman-Casey, Herndon, Coleman, & Lee, 2016). To the author's knowledge, no studies have aimed to quantify the levels of caregiver strain in those providing care to patients with COAG.

The work in this chapter therefore aimed to estimate caregiver strain in people attending a glaucoma clinic, using a widely used and well validated standardised instrument. The primary aim of this work was to compare values from this index to values from other chronic conditions where ICG strain has been investigated using

the same measure, specifically Parkinson's Disease, Motor Neuron Disease and Multiple Sclerosis. This study also tested a secondary hypothesis that measures of worsening VF in COAG would be associated with worsening caregiver strain.

The work presented in this chapter formed a paper published in Eye (Lond.) (McDonald, Turnbull, Chang & Crabb, 2020); see list of supporting publications. The co-authors of this work are Paula Turnbull (PT), Lydia Chang (LC) and David Crabb (DC). Ethical approval was gained by Leanne McDonald (LM) (Appendix 1). Help with recruitment came from PT and LC. Data was collated and analysed by LM. The paper was written by LM, reviewed by DC and approved by all co-authors. The work presented in this chapter has also been presented as a poster presentation at the Association for Research in Vision and Ophthalmology meeting (Honolulu, HA, USA, 2018) and at the United Kingdom and Éire Glaucoma Society Meeting (London, UK, 2018). Additionally, this work has been presented as an oral presentation given at the School of Human and Social Sciences Doctoral Research conference (London, UK, 2018) and the British Congress of Optometry and Vision Science meeting (Cambridge, UK, 2018) ; see list of supporting publications.

4.1 Introduction

Chronic Open Angle Glaucoma (COAG), like many other chronic conditions affecting older adults, does not limit lifespan but can make life more challenging. For example, patients can report significant problems with activities of daily living, such as driving, reading and mobility as their VF worsens (Crabb, 2016; Glen & Crabb, 2015). Such difficulties may lead to a reliance on a spouse, partner, close friend or family member for support (Shtein, Newman-Casey, Herndon, Coleman, & Lee, 2016; Keeffe, Chou, & Lamoureux, 2009). A person caring for someone with a chronic or disabling condition, but not in a formal capacity, can be termed an informal caregiver.

Informal caregiving (ICG), much like the condition that the patient is experiencing, can be a complex issue incorporating physical, psychological, financial and emotional changes (Burleson Sullivan & Miller, 2015). When these experiences are negative, it is termed caregiver strain (Peters, Jenkinson, Doll, Playford, & Fitzpatrick, 2013). For example, informal caregivers have been shown to experience exhaustion, problems with wellbeing and reduced levels of self-esteem (Van den Heuvel, de Witte, Schure, Sanderman, & Meyboom-de Jong, 2001). Informal caregiver (ICG) strain is most likely to affect women and those who do not have adequate social support themselves (Yee & Schulz, 2000; McCullagh, Brigstocke, Donaldson, & Kalra, 2005). Conversely, ICGs who are psychologically well adjusted, have good social support and implement adaptive coping strategies have a

decreased probability of experiencing caregiver strain. ICGs often do not report their caregiver status to healthcare professionals and as such may not receive appropriate support (Royal College of General Practitioners, 2012).

ICG strain is well studied in conditions like cancer (Northouse, Katapodi, Schafenecker, & Weiss, 2012) and mental illness (Chang, et al., 2016) where burden of care is often significant. More recently, ICG strain in long-term conditions has received attention. For example, ICG strain in Parkinson's disease (PD) and Multiple Sclerosis (MS), was found to be significant when measured quantitatively using a modified version of the Caregiver Strain Index (MCSI) (Peters, Jenkinson, Doll, Playford, & Fitzpatrick, 2013). The same may be true for long-term chronic eye conditions. For example, ICG strain has recently been described in people with age-related macular degeneration (AMD) especially as the condition leads to visual impairment (Schmier, Halpern, Covert, Delgado, & Sharma, 2006; Gohil, et al., 2015; Vukicevic, Heraghty, Cummins, Gopinath, & Mitchell, 2016; Hanemoto, Hikichi, Kikuci, & Kozawa, 2017; Gopinath, et al., 2017). Moreover, specific aspects of ICG strain for AMD like that associated with frequent treatment visits to clinic have been flagged (Gohil, et al., 2015; Hanemoto, Hikichi, Kikuci, & Kozawa, 2017). The impact of providing informal care in glaucoma has been investigated previously in interviews with ICGs, but these studies generally focus on ICGs for patients with very poor vision (Shtein, Newman-Casey, Herndon, Coleman, & Lee, 2016) or on ICG strain in paediatric glaucoma patients (Gothwal, Bharani, & Mandal, 2015; Kantipuly, et al., 2019). It would therefore be interesting to investigate whether the issues flagged by Shtein et al. (2016) also occur in ICGs with less severe VF loss. To

the author's knowledge, there has been no attempt to quantify ICG strain in adult COAG and this is the main idea presented in this paper.

This study aims to estimate ICG strain in people in a glaucoma clinic in England with a cross-sectional study using a widely used and well validated standardised instrument (MCSI) (Thornton & Travis, 2003). The primary aim is to compare values from this index to values from other chronic conditions where ICG strain has been investigated using the same measure, specifically those described in Peters et al. (2013) (Peters, Jenkinson, Doll, Playford, & Fitzpatrick, 2013). This study also tests a secondary hypothesis that measures of worsening VF in COAG are associated with worsening ICG strain as measured by MCSI.

4.2 Materials and Methods

A cross-sectional study involving patients recruited from the glaucoma clinic of Hinchingbrooke Hospital (part of North West Anglia NHS Foundation Trust) was conducted. The study was approved by the NHS Research and Ethics committee of the East of Scotland (17/ES/0044 ref number: 216487) and adhered to the tenets of the Declaration of Helsinki. Patient participants were selected consecutively from an Electronic Patient Record (EPR) (Medisoft, Leeds, UK) by the study coordinator (PT) and the clinic's main glaucoma consultant (LC). To be eligible, patients (>40 years) had to be currently treated for a diagnosis of COAG with VF loss in at least one eye. COAG suspects and patients with OHT were excluded. Participants were only included if they had no other ocular disease (except for uncomplicated cataract extraction) and a corrected binocular VA of better than LogMAR 0.3 at their last clinic visit. Patients were selected consecutively from the date they last attended the clinic, and this had to be within 6 months of the data extraction. Names and addresses were recorded along with age (in years) and a measure of VF loss in both eyes (mean deviation; MD) from their last clinic visit as acquired using a Humphrey Field Analyser (Carl Zeiss Meditec, Dublin, CA). The EPR also has a field for the number of significant non-ocular co-morbidities and this number was recorded too.

The aim was to select a total of 250 patients representing a population of people with COAG being treated in a clinic in England (see analysis; sample size). This study deliberately aimed to include 50 patients (some selected non-consecutively) designated as having advanced COAG, defined as MD worse than -12 dB in both eyes.

This measure for advanced VF loss has been widely used before in, for example, health economic evaluations of COAG and coincides with a high likelihood that the patient does not satisfy the VF component for legal fitness to drive (Boodhna & Crabb, 2016; Saunders, Russell, & Crabb, 2012).

A questionnaire pack, including a participant information document, was posted to the address of selected participants. Due to the postal nature of the survey, participants were asked to complete a statement of implied consent (Appendix 2). The patient information document asked participants to identify an informal caregiver (if applicable) with the following question: *'Can you identify someone who is an informal caregiver for your glaucoma? This might be a spouse, a partner, a relative or friend who helps you with any aspect related to your glaucoma.'*

The questionnaire pack included two sections printed on different coloured paper, one for the patient participant and one for their potential informal caregiver (ICG) (Appendix 3). The patient participant section had demographic questions and a validated instrument (EQ-5D) to measure self-reported general health. EQ-5D is commonly used by NICE for health economic evaluations during clinical interventions. The EQ-5D-5L was used, in which items are scored from 1 (no problems) to 5 (severe problems) on the five domains of mobility, self-care, usual activities, pain/discomfort and anxiety/depression. An EQ-5D index score was generated in a standard way with 1 representing full health (a score of 1 on all f items), and, on the basis of a so-called UK tariff (applicable to our participants), a worst health state of -0.594 (van Hout & Janssen, 2012).

If an ICG was identified by the patient, then they completed a separate section of the questionnaire with its own consent statement; this included demographic questions, the EQ-5D and Modified Caregiver Strain Index (MCSI) questionnaires (Thornton & Travis, 2003). MCSI has been widely used with more than 200 citations in the literature. MCSI estimates levels of ICG strain in terms of financial, physical, psychological, social, and personal strain using 13 items, each of which is scored 'yes, regularly', 'yes, sometimes' or 'no'. Scores range from 0 ('no' on all items) to 26 ('yes, regularly' on all items).

The questionnaire pack was sent with two stamped-addressed envelopes to ensure that responses could be returned privately. A 'thank you' note/reminder was sent two weeks later to encourage responses. Data from the questionnaires was double entered. Median imputation was used for any missing values. Data was anonymised and stored in a secure location.

Data analysis

The primary outcome was mean MCSI in the ICGs of the participating patients and a comparison with values reported from a study for ICGs for people with MS and PD (Peters, Jenkinson, Doll, Playford, & Fitzpatrick, 2013); these values were 11 and 12 respectively. From that study the between person standard deviation (SD) for MCSI was 6 units. Therefore, a sample-size calculation for a one-sample t-test aiming to demonstrate a difference of at least 2 units between mean MCSI in our data, as compared to ones described in Peters et al. (power and alpha set at 0.80 and 0.05

respectively) required at least 75 ICG responses. Assuming a response rate of 30% (Peters et al had 37%) meant we aimed to post 250 questionnaire packs.

The secondary aims were to compare MCSI between ICGs of patients with and without advanced VF loss, and then to explore the association between MCSI and worsening COAG as measured by VF loss corrected for other measures, such as sex, age and self-reported general health (EQ-5D). Two-sample t-tests (assumed unequal variances) were used to compare means and Chi-square tests were used for categorical values. Associations were explored with Pearson correlation coefficients and a generalised linear model to correct for covariance. A value of 0.05 was used for statistical significance. Analysis was done in SPSS Statistics 24 (IBM Corp., Somers, NY) and in R (R Foundation for Statistical Computing, Vienna, Austria).

4.3 Results

Invitations were sent to 243 patients falling short of enriching the sample with the target of inviting 50 patients with advanced COAG (n=39). Finding eligible patients fulfilling the advanced VF criteria with preserved VA or not having other ocular pathology was problematic. One-hundred and 16(48%) patients responded. Median (interquartile range [IQR]) time period between a questionnaire pack being posted and returned was 14 (7, 25) days. Mean (SD) age of the patients who responded (n=116) to the postal survey was 73 (10). Mean (SD) best eye MD (BEMD) of the patients who responded was -3.7 (6.4)dB.

Nine patients returned questionnaires declining to take part. Two other patients were not analysed: on checking data entry of the clinical record one was found not to satisfy the inclusion criteria for VA and the other had too many missing items to be analysed meaningfully. This left 105 patients for data analysis.

Only 38 (36%) of the 105 patients analysed had an informal caregiver (ICG). These patients represent just 16% of the total of n=243 contacted, a value lower than anticipated in the sample size calculations (30%) perhaps reflecting that most people in glaucoma clinics do not consider their condition warrants an ICG. This in itself is an important finding in relation to the conditions investigated by Peters et al. (Peters, Jenkinson, Doll, Playford, & Fitzpatrick, 2013) where response rates were higher.

A participant stating that they had an ICG might be related to their marital status. For example, in the patients with an ICG, 87% (33/38) self-reported they were married or in a committed relationship as opposed to being single, divorced, widowed or separated; in contrast this proportion was 60% (40/67) in the patients who did not have an ICG and the difference was statistically significant (p=0.004). Percentage of male participants with and without an ICG was 47% (18/38) and 55% (37/67) respectively; these values were not significantly different (p=0.439)

The primary outcome for the study was Mean (SD) MCSI; this was 2.4 (3.4) in the 38 ICGs who completed the questionnaire (95% CI: 1.3, 3.6). This value was overwhelmingly statistically different (p<0.001, one-sample t-test) from the mean value of ~11 reported in ICGs for people with MS and PD in Peters et al. Moreover, nearly half (n=18; 47%) of this sample of ICG respondents returned a MCSI of zero (indicating no ICG strain, responding negatively to all 13 items). Furthermore, only three ICGs recorded a MCSI >7, a value that some studies have described as meaningful caregiver strain. Taken together these results suggest ICG strain in COAG, as measured by MCSI, is negligible for most of the ICGs of glaucoma patients.

Mean (SD) best eye MD in patients with (n=38) and without (n=67) an ICG was -6.9 (9.1) dB and -2.1 (4.0) dB respectively; these values are statistically different (p=0.004) hinting ICG strain increases with worsening VF loss. Moreover, percentage of patients with an ICG was much higher in patients with advanced VF loss (82%; 9/11) when compared to those with non-advanced VF loss (31%; 29/94) and this difference was statistically significant (p=0.001).

To further highlight this effect of ICG strain being inflated in advanced COAG, **Table 4.1** gives the patient participant and ICG response stratified by our measure of COAG severity. For example, ICG mean (SD) MCSI was much worse when the patient had advanced VF loss (5.6 [4.9]). The three ICGs with MCSI > 7 were for patients advanced VF loss too; this is noteworthy. There was no real evidence to suggest that the sex and age profile, or number of co-morbidities, of the two groups of patients, were different. Yet patients with advanced VF loss, and their ICGs, had worse self-reported general health (EQ-5D) compared to the others in the clinic and their respective ICGs.

Table 4.1 - *Comparison between patients with and without advanced VF loss and their respective ICG responses. Means with standard deviations (p-value for two-sample test [unequal variances]) and numbers with percentages (p value for Chi-square test) are given for the measurements and categorical values respectively. (An asterisk denotes statistical significance at p<0.05.)*

	Patients (n=9) with **advanced VF loss**	Patients (n=29) with **non-advanced loss**	p-value
Patient age (years)	78 (9)	72 (7)	0.077
Patient: female	5 (56%)	15 (52%)	0.841
Better eye mean deviation dB	-21.5 (6.1)	-2.4 (3.2)	<0.001*
Worse eye mean deviation dB	-26.5 (4.9)	-6.8 (5.3)	<0.001*

Patient: EQ-5D score	0.66 (0.21)	0.87(0.15)	0.018*
Patient: Number of co-morbidities	1.9 (2.8)	1.5 (1.4)	0.690
Modified Care Strain Index (MCSI)	**5.6 (4.9)**	**1.5 (2.2)**	**0.040***
Informal caregiver (ICG): number of females	5 (56%)	13 (45%)	0.573
Informal caregiver (ICG) : EQ-5D score	0.77 (0.07)	0.91 (0.12)	<0.001*

Associations of measured variables with worsening MCSI in the 38 patients with ICGs are shown in **Table 4.2**. Worsening VF and poorer self-reported general health (EQ-5D) of the patient were moderately associated with worsening ICG MCSI. This analysis was exploratory because the study was not powered for this. Still, no other variables had a statistically significant association with MCSI. Given the influence of patient EQ-5D the data analysis returned to the comparison of mean ICG MCSI between the patients with advanced (n=9) and non-advanced VF loss (n=29) using a general linear model (sometimes referred to as ANCOVA). After controlling for EQ-5D as a covariate the difference in MCSI between the two groups still remained statistically significant (p=0.035 vs p=0.001 [unadjusted with equal variances assumed]) but the effect diminished with a mean (95% CI) difference in MCSI of 2.7 (0.2, 5.2) reduced from 4.1 (1.8, 6.4) (unadjusted). This analysis still suggests having advanced VF loss inflates ICG strain but in this data this is partly explained by the same patients having a co-varying worse self-reported general health. Of course,

worse general health may or may not be related to having advanced VF loss, but this cannot be untangled with the current data.

Table 4.2 - *Pearson correlation coefficients for different measured variables against MCSI in 38 patients with ICGs. (An asterisk denotes statistical significance at p<0.05.)*

	Correlation coefficient (r)	p-value
Patient age (years)	+ 0.11	0.499
Better eye mean deviation dB	- 0.46	0.003*
Worse eye mean deviation dB	- 0.62	<0.001*
Patient: EQ-5D score	- 0.53	0.001*
Patient: Number of co-morbidities	+ 0.31	0.063
Informal caregiver (ICG) : EQ-5D score	- 0.26	0.113

MCSI items (questions) with the 38 ICG's responses are given in **Table 4.3**. One third of ICGs have at least sometimes made changes in personal plans because of their role. Other relatively more common strains surrounded work adjustments and less time for other family members. MCSI items referring to disturbed sleep, physical strain and a feeling of being 'overwhelmed' were completely rejected by all but a few ICGs.

Some other results from this sample of participants are worth noting. Nearly all patients (98%; 103/105) were Caucasian and 38% (40/105) self-reported being

educated to degree level or higher. In this sample of 38 ICGs there were roughly equal numbers of men (n=18) and women (n=20). Mean (SD) MCSI was similar (p=0.606) for men (2.1[3.6]) and women (2.7 [3.4]) too.

Table 4.3 - *The 13 items from the Modified Care Strain index questionnaire ranked by the frequency of responses by the informal caregivers (ICGs). The top and bottom item in the table represent the item cited as the most common and least common strain experienced by the ICGs respectively. The numbers are rounded whole percent of the n=38 ICGS.*

	Not at all	*Sometimes*	*Regularly*
There have been changes in personal plans because of my caregiving	**66**	31	3
There have been work adjustments because of my caregiving	**76**	16	8
Caregiving is confining/restricting	**74**	26	0
There have been other demands on my time (e.g. other family members need me) which I have been unable to deal with	**76**	24	0
It is upsetting to find the person I care for has changed so much from his/her former self	**79**	18	3
There have been family adjustments because of my caregiving	**82**	18	0
Caregiving is inconvenient	**84**	16	0
There have been emotional adjustments because of my caregiving	**87**	10	3

My caregiving is a financial strain	**87**	13	0
Some behaviour is upsetting (the person I care for has upsetting behaviours)	**89**	8	3
My sleep is disturbed by my caregiving	**89**	11	0
Caregiving is a physical strain	**92**	**8**	**0**
I feel completely overwhelmed by my caregiving	**92**	8	0

4.4 Discussion

A cross-sectional postal survey was used to elicit a measure of informal caregiver (ICG) strain for glaucoma patients in a single clinic in England. Patients were selected consecutively but the sample was enriched with a number of patients with advanced VF loss. Only 36% of patients who responded felt they had an ICG and in these, caregiver strain as measured by a standardised instrument (modified caregiver strain index; MCSI) was negligible. Although, in a subset of patients with advanced VF loss in both eyes, but preserved VA and no other ocular comorbidity, the ICGs response on MCSI was considerably inflated.

Results from this study represent new knowledge about ICG strain in glaucoma patients. This data might be useful for clinicians and practitioners who may not have considered ICG in COAG before. A raised awareness is useful because there is evidence that ICGs who are given adequate support do not experience as much strain (Royal College of General Practitioners, 2012). Moreover, this data might be useful for targeting patients who need extra support in addition to health economic models for glaucoma care (Van den Burg, Al, Van Exel, Koopmanschap, & Brouwer, 2008)

Comparing MCSI values between different conditions seems attractive but is fraught with issues because of the different sampling and methodology used in different studies. For example, CSI (not the modified version) >7 has been reported in 36% of ICGs of people recovering from hip fracture surgery (Ariza-Vega, Ortiz-Pina,

Kristensen, Castellote-Caballero, & Jimenez-Moleon, 2019), 15% of ICGs of people with adult cancer (Hsu, et al., 2017) and 24% of ICGs of people with mild relapsing-remitting MS (van der Hiele, et al., 2019). In contrast this study only had three ICGs with MCSI >7; this could be reported as 3/105 (3%) of people who were contacted/replied, or 3/38 (8%) of ICGs analysed or 3/9 (33%) of the people with advanced COAG; these different figures illustrate how sampling can affect results. The results of this study were aligned to Peters et al (Peters, Jenkinson, Doll, Playford, & Fitzpatrick, 2013) but even their study had different methodology to the current study. Still, for the primary outcome, mean MCSI for ICGs of patients in glaucoma clinics was considerably lower than values estimated by Peters et al. for MS and PD.

Greater ICG strain being related to worse VFs is another novel finding of this study; the association was true in the least and most affected eye. Mean MCSI was three times larger in this sample of patients with advanced VF loss compared to other patients in the clinic; this co-varied by the patients self-reported general health-related QoL (EQ-5D) but the effect remained after EQ5D score was statistically corrected for in the MANCOVA. This result is unsurprising because studies have indicated a rapid decline in vision related QoL in COAG as both eyes progress to end stage VF loss (Peters , Heijl, Brenner, & Bengtsson, 2015; Jones, Bryan, & Crabb, 2017) and this likely reflects the greater help these people need. Of course, the findings of this study add to the evidence that halting VF progression is a clinical imperative, not just for the patient but also for the wellbeing of the ICG of a patient. A longitudinal study would be needed to explore how ICG increases as COAG

progresses in an individual and this could untangle the effect from declines in general health.

ICG strain in another age-related eye condition, AMD, has been explored but making comparison with these studies is also tricky. For example, a study specifically assessed people on ranibizumab (injection) therapy for neovascular AMD and found it was associated with significant ICG strain (Gohil, et al., 2015). Other studies have highlighted ICG strain in AMD but none sampled consecutively from people in clinics nor used MCSI, so it is difficult to make comparisons (Schmier, Halpern, Covert, Delgado, & Sharma, 2006; Vukicevic, Heraghty, Cummins, Gopinath, & Mitchell, 2016). A large multicentre cross-sectional study conducted in Portugal demonstrated visual impairment, defined as worse than 0.30 logMAR (Snellen 6/12) in the better seeing eye, incurs ICG strain (Marques, et al., 2018). This research, however, measured ICG strain in terms of the self-reported number of hours of informal care provided per year (reported by the patient). This may present a problem because other studies have demonstrated that patients' and caregivers' experiences of informal care are often different. Patients may therefore underreport the amount of care provided (Doekhie, Strating, Buljac-Samardzic, van de Bovenkamp, & Paauwe, 2018). The results in this study from patients with advanced VF loss add to this knowledge because ICG strain was measured by ICG self-report and using a validated measure (MCSI). This study also adds new knowledge because the results showed inflated ICG strain but, because of the study design, the VA of participants was better than 6/12. This means we can be more confident that the relationship found in this study between MD and ICG strain is valid.

There are good explanations for why ICG strain was insignificant in the majority of this sample of patients. Many of these patients are receiving treatment for a condition that is almost always asymptomatic until advanced in nature. In addition, patients had relatively preserved VA and no other ocular morbidity. In addition, although MCSI is widely used, it is unlikely to capture specific ICG strain for people with COAG. For example, it was obvious that some MCSI items (**Table 4.3**), like care being physically draining, were rejected. Analogous to this issue is the debate about items within patient reported outcome measures (PROMs) that are not glaucoma specific and how they might, for example, be insensitive to glaucoma progression (Skalicky, Lamoureux, Crabb, & Ramulu, 2019; Jones, Garway-Heath, Azuara-Blanco, Crabb, & UKGTS Investigators, 2019).

It is reasonable to speculate there may be ICG strain in COAG around the different treatments (drops/surgery) and this could be the subject of future work. Other idiosyncratic ICG strains for COAG might include the psychological burden of having a potentially blinding condition or loss of visual function that might restrict mobility or remove a driving licence. We know patients are very concerned about the latter (Bhargava, Bhan-Bhargava, Foss, & King, 2008) and this would likely impact on their ICG too. Qualitative analysis of interviews with patients and their ICGs could pinpoint these strains; this is the subject of further work presented in **Chapter Five** of this thesis. In turn, this research could lead to development of a simple COAG specific instrument that could be administered in a clinic to detect if there was a 'silent' developing ICG strain. Others have discussed the importance of identifying a *precipice* when patients lose self-medicating capability, and this might be

identifiable with an appropriate instrument for the ICG (Read, et al., 2018). Furthermore, there was a lack of patients in the EPR who satisfied the criteria for advanced VF loss. Participants with advanced VF loss in this study had a mean (SD) MD of -21.5 (6.1) dB in their better eye, whilst the criteria for advanced VF loss was an MD of worse than -12dB in both eyes. This distinctly high level of VF loss may be responsible for the differences found between the groups. As both better and worse eye MD were found to significantly predict ICG strain in this study, future research should consider using a binocular measurement of VF loss as a surrogate for visual function rather than implementing monocular criteria (Asaoka, et al., 2011).

Other results from this study are worth discussing. The high number of patients who declared not to have an ICG is interesting too. This might suggest that patients do not consider their COAG warrants an ICG. Yet there was a strong link between having an ICG and being married or having a partner. In turn this highlights the importance of identifying patients who may be socially isolated or living on their own. Moreover, in this data, there were no differences in the sex profile of the ICGs with men and women reporting the same level of ICG strain. This contradicts studies where ICG strain has been thought to be something that affects women more than men (Yee & Schulz, 2000; McCullagh, Brigstocke, Donaldson, & Kalra, 2005).

This study had several strengths. A widely used, standardised instrument was employed; the sampling was conducted carefully; and the study considered other variables allowing for an analysis that corrected for covariates. At the same time this study has several limitations. The sample came from one centre; the patients were

nearly all Caucasian and education levels were relatively high. Some studies have indicated that there may be cultural and ethnic differences in the experience of ICG strain (Haley, Roth, Howard, & Safford, 2010). VF records were extracted from an EPR and may have changed in the maximum six-month period before a participant responded, although this is unlikely. Moreover, this study was only cross-sectional, relied on self-report and could only examine associations.

In conclusion, this study is novel in assessing ICG strain in patients from a glaucoma clinic. The data demonstrates that ICG strain in the great majority of these patients is largely negligible but, importantly, it worsens as disease severity worsen. Patients with advanced VF loss in both eyes have considerably inflated ICG strain although some of this might be explained by worsening general health in these people too. Further work should be done to improve our understanding of the specific nuances of ICG in relation to COAG.

Chapter Five – Why Do Carers Care? Experiences of Informal Caregiving in Glaucoma.

Patient reported outcome measures (PROMs) provide us with some information about the experience of providing care for patients with chronic illness. However, they are limited as they do not provide information on the specific nuances of the condition. In COAG, it has been demonstrated that caregivers' express concerns about the lack of patient education and patient's reliance on caregivers. Caregivers express further concerns about the development of maladaptive coping mechanisms (Shtein, Newman-Casey, Herndon, Coleman, & Lee, 2016; Waisbourd, et al., 2016). Studies have suggested that caregivers, much like patients, go through a process of adjustment to the disease that relies on knowledge and the possible consequences of the illness (Kennedy, et al., 2017). However, our knowledge of the experience of this process in COAG is limited.

We do not know, for example, the role that caregivers play in COAG management, the experience of giving/receiving care and the reasons why COAG patients may (or may not) need an ICG. This study aimed to investigate these questions using focus groups analysed by interpretative phenomenological analysis (IPA) in order to better understand patient and ICG experiences of caregiving in COAG. Specifically, this work aimed to answer the question; '*What are the factors that form the experience of informal caregiving in COAG?*'

The co-authors of this work are Paula Turnbull (PT), Lydia Chang (LC) and David Crabb (DC). Ethical approval was gained by Leanne McDonald (LM). Participants

were recruited from Hinchingbrooke hospital by PT and LC. The focus groups discussed in this chapter were conducted by LM with PT acting as an observer. Data was analysed by LM and reviewed by DC.

5.1 Introduction

COAG is associated with a variety of self-reported problems in activities of daily living, such as driving, reading and mobility, particularly when it is in the advanced stages (Crabb, 2016). However, patients with more moderate VF loss also report complex functional issues (Ramulu, et al., 2014) and may avoid certain activities as a result (Glen & Crabb, 2015). This in turn may lead to an increased reliance on family members or friends for support with activities, which is termed *informal caregiving* (Shtein, Newman-Casey, Herndon, Coleman, & Lee, 2016; Keeffe, Chou, & Lamoureux, 2009; Schmier, Halpern, Covert, Delgado, & Sharma, 2006). The experience of being an ICG, which incorporates physical, psychological, financial and emotional changes is likely far more complex than the scope of the current tools designed to measure it. In clinical consultations alone, the ICGs may take on roles such as memory aid, emotional support, clinical decision maker, elaborator, advocate, interpreter, company provider, or transcriber (Ellingson, 2002). Successful ICGs can benefit a patient in terms of condition specific activities (taking medications appropriately) and general activities (self-care), as well as minimising the risk of maladaptive emotional responses such as depression (Sayera, Riegel, Pawlowski, Coyne, & Samaha, 2008; Applebaum, et al., 2014). However, this relies on the ICG having the expertise and knowledge to help with management of the condition (Borgermans & Devroey, 2017).

Previous research with ICGs for patients with COAG has shown ICGs had minimal levels of engagement with the condition and expressed concerns about the lack of

patient education, patients reliance on ICG support and the development of maladaptive coping mechanisms (Shtein, Newman-Casey, Herndon, Coleman, & Lee, 2016; Waisbourd, et al., 2016). Negative feelings toward the ICG role have been shown to affect the wellbeing of both patient and ICG (Fingerman, Pitzer, Lefkowitz, Birditt, & Mroczek, 2008). Where ICGs feel obligated to help the patient with their condition, there is a risk that they may develop psychological ambivalence (contradictory feelings about the patient) (Connidis & McMullin, 2002), which may impact long-term relationships.

There is also evidence that patients with COAG fear becoming burdensome on their friends and family and that this can lead to self-imposed restrictions in activities (Glen & Crabb, 2015). These restrictions could lead to the patient experiencing isolation and social disconnectedness. In patients with osteoporosis, maintaining physical activities was important for maintaining long-term psychological and physical health (Kerr, et al., 2017). Moreover, it has been demonstrated that perceived isolation is an important indicator of poor mental health (York Cornwell & Waite, 2009).

There is limited knowledge about experiences of ICG in patients with COAG, but current literature does suggest that there may be specific concerns that need to be addressed. These include questions surrounding the role of the ICG, the experience of giving/receiving care and the reasons why patients may need an ICG. This study therefore aims to investigate these broad questions using focus groups analysed by interpretative phenomenological analysis (IPA) to investigate patient and ICG

experiences of caregiving in COAG. Specifically, this work aims to answer the question; '*What are the factors that form the experience of informal caregiving in COAG?*'

5.2 Materials and Methods

Design

This study uses focus groups analysed by interpretative phenomenological analysis (IPA) to investigate patient and caregiver experiences of caregiving in COAG. IPA is an idiographic qualitative analysis approach concerned with understanding the lived experience of an individual and the meaning placed on these experiences (Smith & Osborn, 2012). IPA methodology has been widely used in the health professions in order to understand healthcare and illness from the patient perspective (Biggerstaff & Thompson, 2005).

Focus groups took place at one clinical centre in England (North West Anglia NHS Foundation Trust; Hinchingbrooke Hospital) across two days in July 2018. A purposive sample was initially recruited from a list of participants who had previously participated in the study presented in **Chapter Four**. Thirty-three participants with a range of disease severities were invited by telephone to take part in two focus groups. To be eligible for the study, patients had to be > 18 years and have a clinical diagnosis of COAG. Participants were only included if they had no other ocular disease (except for uncomplicated cataract extraction) and a visual acuity of better than 6/12 in at least one eye. All participants had measurable visual field (VF) loss in at least one eye. VFs were measured in clinic using a Humphrey Field Analyser (HFA; Carl Zeiss Meditec, Dublin, CA) using the Swedish Interactive Threshold Algorithm (SITA Standard 24-2).

Previous research has indicated that the optimum number of participants for a focus group is 6-8 (Bowling & Ebrahim, 2005). We therefore aimed to recruit 6-8 individual participants for a 'no caregiver' focus group (Group A), which acted as a comparison group during the analysis and 3-4 pairs of participants for the 'caregiver' focus group (Group B). Seven individuals agreed to take part in Group A, however three participants opted out of the study on the day due to sickness. Group B consisted of four pairs of participants (8 participants in total). The final sample consisted of 12 participants, 8 of which were patients and 4 of whom were caregivers.

Procedure

To prepare for the focus groups, LM and PT reviewed the semi structured interview schedule for familiarity (Appendix 4) and the audio recording equipment was tested. The focus groups took place in a meeting room at Hinchingbrooke hospital and signposting was provided from the hospital entrance. It was anticipated that the focus groups would last 90 minutes (including the consent procedure), and the room was booked for 180 minutes to ensure that participants would have enough time to discuss their experiences. A copy of the participant information sheet, consent form and debrief sheet were printed out for each participant and LM and PT greeted participants as they arrived. Participants were also provided with refreshments. All participants were asked to read a participant information sheet upon arrival at the hospital. They were then asked to provide written consent to take part in the study, with the exception of one participant in Group B (B1) who,

due to their advanced VF loss, asked the researcher to read the participant information sheet and provided verbal consent. The focus groups were led by the primary researcher (an experienced qualitative researcher) using a semi-structured interview schedule (Appendix 4). The focus groups lasted 47 minutes and 63 minutes for groups A and B respectively. Both focus groups were audio recorded and transcribed verbatim.

The five step IPA process involved initially reading each transcript several times for meaning and making initial notes to ensure that the primary researcher had a good sense of the data. Secondly, initial themes were developed from the codes; similar themes were clustered together in order to create superordinate themes. Each of the superordinate themes existed across both transcripts. The final step was to create a master table of themes. The themes were reviewed by the co-authors.

The study was approved by the NHS Research and Ethics committee of the East of Scotland (17/ES/0044 ref number: 216487) and it adhered to the tenets of the Declaration of Helsinki. All participants gave their informed consent prior to taking part. Data from the focus groups was transcribed verbatim, anonymised and stored in a secure location.

5.3 Findings

Patient participants in Group A and Group B had a median (IQR) age of 71 (62 to 81) and 77 (67, 87) respectively (**Table 5.1**). Participants were all educated to a high school level and were all Caucasian. Six of the eight participants (75%) were married, one participant was single, and one participant was widowed. In Group A, mean (SD) HFA mean deviation was -2.33 (-3.46) dB and -7.93 (-3.51) dB in the better and worse seeing eye respectively. In Group B, mean (SD) HFA mean deviation was -8.21 (-4.71) dB in the better eye and -14.96 (-2.91) dB in the worse eye.

Table 5.1: *A summary of patient's vision and demographic information*

	Patient sex	**CG sex**	**Marital status**	**Age**	**Left eye HFA mean deviation (dB)**	**Right eye HFA mean deviation (dB)**
Group A						
A1	F	-	Married	62	-11.31	-0.60
A2	M	-	Married	82	-10.61	-7.51
A3	M	-	Married	78	-0.80	-4.79
A4	M	-	Single	64	-5.00	-0.39
Group B						
B1	F	F (B5)	Widowed	90	-16.91	-13.94
B2	F	M (B6)	Married	75	-10.97	-10.00
B3	M	F (B7)	Married	65	-17.33	-3.40
B4	F	M(B8)	Married	80	-14.62	-5.5

Interpretative phenomenological analysis revealed three superordinate themes in relation to the experience of informal caregiving in COAG. Broadly, the caregiver

experience consisted of an obligation toward the patient, mediated in Group B by positive outcomes and feelings of empathy for the patient's circumstances. Caregivers and patients also stressed the importance of the caregiver in effective communication with care teams. Loss of independence appeared to be the defining feature in increasing care needs, with participants in Group A expressing more individualistic beliefs and participants in Group B stressing the importance of collaborative care.

Communication with care teams

Better communication with physicians/care teams was identified as an important factor for patients with a caregiver. Patients in Group B stated the importance of having a caregiver present during hospital appointments. The role of the caregiver in the context of appointments varied amongst participants, but primarily, the caregiver's role comprised of taking notes and assisting the patient with synthesising and understanding the information that was being communicated by care teams.

'I think it's always been a good thing to have [name omitted] in the consulting with us when you're having the eyes tested and when you're being looked at because they're asking you various questions and you're going through it. There's [sic] drops in your eyes and the eyes are stinging and everything else, and yes, you are asking questions but at the same time, I don't think you're taking it all in, where [name omitted] is. [Name omitted] is taking it all in. I'm coming out and saying 'well, he's said this' and she's saying 'no, I don't think he did, he said this and he meant that' so you've always

got another idea of what's going on there and what's happening.' **B3, M, moderate VF loss***.*

Caregivers in Group B expressed the importance of being present for investigations in order to relay information or ask questions. They expressed sympathy for patients who were not accompanied to their appointments.

'So I, I think that's very important actually, that somebody has got the support – if I'm able to give it to [name omitted] or you're able to give. I think that should be encouraged. When I sit in the clinic waiting, we all sit in the clinic waiting the hours, but you see the odd person go through on their own and I actually feel for that person. They call a name and the person gets up and goes.' **B6, M, wife moderate VF loss.**

Participants within Group A also unexpectedly identified that they found it useful to have a caregiver present when attending hospital appointments. These participants seemed not to view attending appointments as part of a caregiver role, but rather 'help'.

'In fact, whenever I go, if my wife can come with me – and very often she needs to if I am having drops, of course, for driving – then she will take notes. I don't - I just need to concentrate on what's going on. It's a great help, yeah. Because I think otherwise it is – somebody's – if somebody's doing a field of vision test and saying something, you can't sit there and write things down that you want to remember.' **A2, M, moderate VF loss.**

Caregivers in Group B also stressed the importance of being given sufficient information regarding patient outcomes so that they had an understanding of what

the patient was likely to experience. The discourse around outcomes in Group B primarily addressed surgical outcomes. Caregivers expressed frustration at not being aware of the potential outcomes of surgery.

'From my perspective, and probably [name omitted] as well, had we have known – and maybe that information isn't out there. Maybe there isn't the information out there to know that if you're in that small percentage of where the trabeculectomy fails, what then are the long term effects, the amount of drops you will need to use, the possible discomfort, the change all the time in your prescription for vision? Because I think that's worn you down.' **B7, F, husband moderate VF loss.**

Not receiving adequate information regarding appointments was also identified as a major frustration by caregivers in Group B. Caregivers discussed an important element of their role consisting of communicating with the hospital to ensure that regular monitoring appointments were provided. The frustration expressed, suggested caregivers felt their loved one would be overlooked if it weren't for their pro-active role in relaying information about appointments.

'Also, I think the other frustration is that you go to the glaucoma clinic and they say, 'yes we'll see you in three months'. Three months comes and goes, and you don't hear anything. Then it goes four months, five months and you still don't hear anything. So you end up having to phone them and say 'when are we going to come?'. 'Oh, oh, oh, oh yeah. Oh yeah we'll get you in, we'll do you in another two months'. They end up – what should have been a three month follow up we do six months or longer. It would have

gone even longer if you hadn't chased it. There can be significant changes, as we all know, in that time period.' **B5, F, mother severe VF loss.**

Overall, communication with physicians and care teams seemed to be a core element of the caregiver role in COAG. Participants in Group A also expressed this, despite not identifying a caregiver as part of the study. This suggests that family and friends may play an important role in the understanding and management of COAG, regardless of the label assigned.

Obligation toward patient

Caregivers in Group B used language, which suggested that they felt a certain amount of obligation toward the day-to-day management of COAG. This sense of obligation was often expressed in the context of administering medication.

'It's very difficult if one is going out. You think 'oh no, I'm not going to be back in time for the eye drops' and this sort of thing. You're not just thinking of yourself. You're having to think of...[pause] well, you need to be there to get the drops in.' **B5, F, mother severe VF loss.**

In previous literature, caregivers for patients with visual impairments have expressed guilt and this may impact the relationship between patient and caregiver in the long term (Vukicevic, Heraghty, Cummins, Gopinath, & Mitchell, 2016). In this study, however, the sense of obligation seemed to be mediated by positive outcomes for the patient and most caregivers who expressed these feelings did not describe a sense of guilt.

'I accept that we do drops at night or whatever, but honestly, personally it's made no difference to me at all. But the other gratifying side is an improvement in the eyes. We've had a trabeculectomy in one eye and a stent in the other eye. We go back next week, or in 10 days to get that final result, if the pressures have dropped everyone's all quite happy. You know what I mean? That in itself has been worth me doing a few drops at night.' **B8, M, wife moderate VF loss.**

Some patients in Group B, however, expressed a degree of guilt and self-blame that their caregivers felt the obligation to administer medication.

'...but when I have the operation and there's a lot of bottles and I cannot press them. So, if I'm out somewhere, somebody else has to do them. But other than that [name omitted] has to do them. That's the only bug bear, and that's my fault, not his.' **B2**, **F, moderate VF loss.**

Caregivers in Group B discussed their obligation toward helping the patient maintain their independence, particularly post-surgery, in hopes of improving the patient's QoL and speeding up recovery. These feelings seemed to arise due to empathy with the patient's circumstances.

'Well yeah, because you do constantly think when someone is recovering from something, that part of the rehabilitation is to get them out and about because we all know that if you're unwell – because after surgery you are. Even if you know there's going to be recovery because most of these things are flexible in the long term. Part of that is getting well. You would be thinking – each day I would programme in – more so than we would ordinarily have lived our lives, take him to the garden centre, take him

to this, do that, because you're constantly aware that might improve recovery.' **B7, F, husband moderate VF loss.**

Participants in Group A expressed the importance of the support of their loved one's post-surgery, but in contrast to Group B also stressed the need for any interventions to also fit around their own personal plans.

'I was mostly self-sufficient. I remember feeling really fortunate that the date of the operation came through and it was – because I work school hours, it was lumped on to the February half term and I remember thinking 'oh great, I've only got to take one week off school instead of two'. It's funny, the things that go through your head at this time. But yes, afterwards, my husband was very closely involved in administering all the drugs because, as you know, some have to be every hour all day. Every waking hour. So, there's quite a lot to remember. He was quite instrumental in making sure I did that properly. But everything else was fine.' **A1, F, moderate VF loss**

It's unclear from the accounts in Group A, whether this sense of obligation toward the patient was present, but the patient's description of their partner being *'quite instrumental in making sure I did that properly'* suggests a degree of responsibility.

Losing independence

A theme that was commonly expressed by participants in Group A was the importance of maintaining their independence, whilst the participants in Group B stressed a more collaborative approach to their health, which involved their caregiver at all stages. Participants in Group A anticipated that worsening disease

and subsequent loss of independence may lead to increased care needs, and that this was likely to impact on their emotional functioning.

'As the disease progresses and has a physical impact where maybe – I hope in the distant future – I might need some form of physical support to get around. Obviously, I won't be able to drive and all these things that I anticipate might happen. I suppose it might have a psychological impact, whereas my life hasn't changed very much, apart from having operations and attending appointments and putting in drops daily. All that is very important of course, you never forget it. It's always in the back of your mind. But I think once it starts to impact your life, and maybe losing independence in the future, I think then it might have a psychological impact.' **A1, F, moderate VF loss.**

Driving was the primary factor discussed by participants in Group A. All participants in Group A expressed concern about the impact that losing their driving license would have on their wellbeing.

'I think, for me, I share the view that I'm okay, if you like. I haven't had a situation where I've had to – where I've failed my eye test for driving, which would have a major impact on my life, I would think, if that happened. But I feel fairly secure in that I have issues with one of my eyes but the other one I've got extremely good vision on. So, I don't think I've going to have to face that challenge. Certainly not on the next review.' **A3, M, early VF loss.**

Other participants who identified concerns expressed that these challenges were not an immediate concern, rather something that could be faced at a later date, and stressed the importance of support services being in place at this stage.

'I can imagine that having some sort of access to – almost like the Samaritans for people who are suicidal, for somebody to ring up and say 'this is what I'm afraid of, what should I do?', who can perhaps point me in the right direction. I can see that sort of service being very valuable. It doesn't sound like we [the group] would need to ring it, but I can imagine quite a lot of situations where people might. People who have perhaps got sight deterioration in excess of ours.' **A4, M, early VF loss**

Fear of going blind was expressed by reflecting on the experiences of others rather than the patient's own experience. Framing fears in this way may be an attempt to dissociate from the negative group identity of 'glaucoma patient', which may act as a protective factor for psychological wellbeing (Weiss & Lang, 2012).

'You watch these things about people who have had massive degeneration and things like that and they do become very lonely and very introspective and very depressed because the loss of any sense, but your sight in particular, does affect your whole life. There's so many things you can't do, you can't enjoy. You can't read, you can't watch television, you can't drive, you can't see the countryside. There's so much you're missing out on losing your sight. If you go deaf, okay, you can't hear, but you get subtitles, it's not the end of the world. Going blind must be absolutely terrible and knowing that you're going blind must be even worse.' **A2, M, moderate VF loss.**

Participants in Group B had less fears surrounding loss of independence and appeared to have a more collaborative attitude to their COAG management, which involved the caregiver having a high level of knowledge about the condition. This high level of disease knowledge may give caregivers increased confidence in carrying out their caregiving tasks (Mok, Chan, Chan, & Yeung, 2013).

'I think, from a carer's point of view, there's been lots of information – and in fairness - I've probably read a lot more of it than [name omitted] has. There is the information. We didn't feel at any point that we couldn't have rung and had the support. We had a specialist eye nurse than we could have rung pretty much 24/7.' **B7, F, husband moderate VF loss.**

5.4 Discussion

In this study, a focus groups design was used to investigate experiences of caregiving in glaucoma in a single clinic in England. Participants were selected purposively based on self-identified caregiver status. This was to ensure that comparisons between experiences in different patient groups were possible using interpretative phenomenological analysis (IPA). This research aimed to answer the question; '*What are the factors that form the experience of informal caregiving in COAG?*' From the qualitative synthesis, it emerged that participants with an ICG stressed the importance of their ICG being involved in communicating with care teams and administering medications. ICGs felt a sense of obligation toward the patient, but this was not generally associated with negative emotions. Those without an ICG feared a loss of independence more than those with an ICG. This study speculates that aspects of COAG management, which are generally considered to primarily involve the patient, (e.g. hospital visits, taking medications) may need to include an ICG in order to inform successful health behaviours for some patients.

Results from this study represent new knowledge about the experience of being an ICG for a glaucoma patient, and the experience of having an ICG from the patient perspective. This data might be useful for clinicians and practitioners who may not have considered ICG in COAG before. Particularly in a clinical setting, where it has been demonstrated that having an ICG present during consultations can help improve communication. Additionally, an ICG may be useful for when the clinician is attempting to gather information on medical history and monitor symptoms

(Laidsaar-Powell, et al., 2013). Moreover, this data might be useful for targeting advanced glaucoma patients without an ICG to prevent isolation and poor medication adherence in this population.

The sense of obligation reported by ICGs in this study is another novel finding. This may be particularly important, because previous research has demonstrated that family ICGs who feel a sense of obligation to provide care and are unable to exercise their own agency, are more likely to experience psychological ambivalence (contradictory feelings or emotions about their family member) (Connidis & McMullin, 2002). One of the participants in Group B, the daughter of the patient, highlighted that they felt a sense of obligation to administer eye drops and that they felt guilt when they were unable to do this because of personal plans. This may be an interesting avenue for future research, as it has been demonstrated that ambivalent adult parent- child relationships may affect the long-term psychological wellbeing of both parties (Fingerman, Pitzer, Lefkowitz, Birditt, & Mroczek, 2008). However, other participants in this study reported that their caregiving role was rewarding. Research in ICGs demonstrates that many who provide informal care for family members with a serious illness reported that their role was rewarding, allowing for stronger personal relationships (Anderson & White, 2018). It may be important then for clinicians or support groups to recognise the diversity of responses in providing informal care and target support or intervention appropriately.

Results of this study also support the findings of previous research that indicate there may be a *precipice of care* in COAG when patients lose the ability to self-administer medication (Read, et al., 2018). Several participants in Group B highlighted problems with administering their own drops, and for some ICGs, administering drops and attending hospital appointments were their only care responsibilities. On the other hand, none of the participants in Group A reported problems with administering their drops. One participant did describe the involvement of her husband in drop administration post-operatively, as she was unable to administer her own medication. This supports the idea that care needs in COAG may be determined by the ability to administer medications. It may also be argued that the precipice of care in COAG could extend beyond medication administration. Many of the participants in Group A reported fears of losing their independence in other domains, particularly losing their driving license. This finding is very similar to findings found in qualitative investigations of experiences in patients with early dementia, where loss of self and protrusive knowledge of the condition becoming worse were mapped on to the CSM domains of identity and understanding (Harman & Clare, 2006). Previous research has demonstrated that losing the ability to drive is a key concern for COAG patients (Bhargava, Bhan-Bhargava, Foss, & King, 2008). This fear of losing independence may be partly mediated by patients' fear of becoming a burden on family and friends (Glen & Crabb, 2015). Therefore, in future research, the idea of the existence of a precipice of care should also be investigated in relation to losing the ability to drive.

This study had several strengths. To the author's knowledge, this is the first study to use interpretative phenomenological analysis to investigate experiences of COAG. Because it is a purely idiographic approach and each case is considered individually before themes are generated, IPA allows for a detailed examination of lived experience, free from the confines of pre-existing theoretical conceptions (Smith & Osborn, 2015). The use of focus groups with open ended questions allowed for richer data collection, as the lead researcher designed the questions to reflect a broad range of topic areas (caregiving role, experience of caregiving, support for caregivers/patients) rather than focusing on specific issues (e.g. the role of the caregiver in administering medication). This allowed the participants to create and steer their own dialogue with minimal intervention from the researcher (Smith & Osborn, 2012). Focus groups may provide a richer dialogue when compared to traditional semi-structured interviews, due to the diversity of the participants. On the other hand, the use of focus groups, rather than one-to-one semi-structured interviews, led to some participants being more dominant in the dialogue (for example, B3 and B7 (husband and wife) in Group B). This presents a problem because it is likely to have affected the quality of the dialogue from the other participants. However, focus groups and IPA, when used together, did produce detailed information about the experience of having an ICG in COAG and allowed for direct comparison of experiences with patients who did not have a caregiver. Moreover, VF records were extracted from an EPR on the day of the focus groups, so they provided an up to date estimate of the participant's vision at the time of the study. Using two different populations and comparing their experiences allowed us

to investigate the idea that a precipice of care may exist in COAG management and add ideas to literature already published on this topic.

There were also several limitations to the study. For example, the optimum number of participants for a focus group is 6-8 (Bowling & Ebrahim, 2005). The current study was only able to recruit enough participants to Group B (n=8), with only four participants (out of seven who had agreed) attending in Group A. This may affect the transferability of the results to a wider population of COAG patients and caregivers, due to the limited number of opinions that were analysed. In addition, the number of focus groups may also have been problematic. A large thematic analysis of 40 focus groups suggested that around 80% of themes were discoverable with two to three focus groups, but that the optimum number of focus groups is between three and six (Guest, Namey, & McKenna, 2017). However, due to the more idiographic nature of IPA compared to thematic analysis, a sample size of between four and ten participants is generally considered optimal (Hefferon & Gil-Rodriguez, 2011). There is a risk, however, that data saturation was not reached in this study and this is an important limitation to consider when assessing the dependability of the results. Many of the participants in both Group A and Group B reported other health conditions during the focus groups, but this information was not formally recorded. This may be important because around 65% of older adults between 64 and 85 years old have more than one co-morbid chronic condition (Banerjee, 2015). Due to the study design, this study may have captured the experiences of co-morbid conditions in an informal capacity. Future research should aim to include this more explicitly in any conversation about ICG in COAG. This study also did not consider

personality as a factor, which may be important because we know that patient personality can affect the response to chronic illness (Furnham, 1989; Williams, O'Connor, Grubb, & O'Carroll, 2011). Further evidence shows the personality of the ICG can be influential on the patients' physical and mental health, and that this is mediated by the ICGs perceived ability to successfully manage the condition (Lockenhoff, Duberstein, Friedman, & Costa Jr, 2011).

In conclusion, this study is novel in investigating the experience of having an ICG in COAG. The data demonstrates that having an ICG may be most likely when loss of independence occurs, and that this is something that patients without an ICG fear. ICGs in this study played a key role in communication with care teams, which may have benefits for both patients and clinicians. Further research should be undertaken to investigate the influence of self-efficacy and personality on CG experiences and to identify whether certain groups, such as divorced or widowed COAG patients with advanced VF loss, are at risk of poor management due to the unavailability of family caregivers.

Chapter Six – Summary of Main Findings and Future Work

6.1 Summary of Main Findings

The aim of this work was to explore the experience of living with Chronic Open-angle Glaucoma (COAG). Specifically, to investigate the cognitive and emotional processes that may be involved in illness management from the perspective of both the patient and their immediate social support network (informal family caregivers). This work supports existing literature on the patient experience of COAG as a chronic illness and suggests the consideration of some external factors in order to fully capture this experience. Both quantitative and qualitative methodologies were employed to investigate the aims and research question of this thesis appropriately. This thesis identified and addressed prominent gaps in the literature surrounding the lived experience of COAG and these are summarised here.

The study reported in **Chapter Two** was the first to measure illness representations in newly diagnosed patients with COAG/OHT. A comparison of illness representations of patients with a diagnosis of between 2 and 5 years can then be formed, allowing us to investigate the nature of illness representations over the course of the disease process. This study provided evidence that when personality type and general health are considered, newly diagnosed patients with COAG have marginally more positive perceptions of life in general, experience of symptoms and "understanding" of their condition (all $p<0.01$). In contrast, COAG patients with a diagnosis >2 years understood better their condition was long-term ($p<0.01$). These

results suggest that COAG diagnosis may not be as distressing as previous studies have indicated (Hartmann & Rhee, 2006; Lacey, Cate, & Broadway, 2009; Odberg, Jakobsen, Hultgren, & Halseide, 2001). Interestingly, no differences in illness representations were found between patients with OHT and patients with COAG and there were no differences in the OHT group who were newly diagnosed, compared to those who had an established diagnosis. One possible explanation for this novel finding is that OHT patients may be employing the 'no symptoms, no asthma' belief when it comes to their condition (Halm, Mora, & Leventhal, 2006). This is a maladaptive coping mechanism where the diagnosis is essentially ignored until it starts to present symptoms. It is thought that this thinking could shield patients from negative emotional responses to illness, such as anxiety and depression (Scharloo, et al., 1998; Llewellyn, McGurk, & Weinman, 2007). Patients with OHT do not experience symptoms from their condition, and this may explain their remarkably positive illness representations and the finding that there were no differences between cases and controls. The similarity of illness representations between the OHT and COAG patients also indicated the need for better communication of the diagnosis of OHT and appropriate advice on the actual long-term risk of VF loss in this population. Participants with an established diagnosis did not feel as positive about life in general and did not feel that they understood their condition well, despite this group not having worse VF loss than the group of newly diagnosed participants. This may be reflective of the largely idiopathic nature of COAG. Patients with a strong illness identity demonstrate more positive illness representations overall (Hale, Treharne, & Kitas, 2007) and are more likely to

engage with recommended treatment programmes (Hemphill, Stephens, Rook, Franks, & Salem, 2013). Results of this study indicated that COAG patients had poor understanding of their condition and indicated that they had little confidence in their treatment. This supports previous qualitative studies on illness representations in COAG, which demonstrated that those with a fragmented illness identity were less likely to adhere to treatment (McDonald, Ferguson, Hagger, Foss, & King, 2019). Although this study presents a novel and interesting view of the possible changes to cognitive representations of illness over the course of the disease, it is important that these results are interpreted with caution, as illness representations form along on individual level and are influenced by factors such as life experience and personality (Petrie, Jago, & Devcich, 2007). This means that group comparisons may be limited in their usefulness.

The study reported in **Chapter Three** tested the feasibility of a multi-faceted online self-monitoring tool designed to enable the patient to become more involved in their COAG journey through self-monitoring visual symptoms and keeping a diary of their experiences. This study provided insight into the emotional representations involved in living with COAG. Previous studies investigating the emotional response to COAG have been conducted but mostly with newly diagnosed patients (Hartmann & Rhee, 2006; Lacey, Cate, & Broadway, 2009; Odberg, Jakobsen, Hultgren, & Halseide, 2001). Results showed good uptake of the self-monitoring exercise, with 96% of symptom monitoring questions completed and participants recording a median (interquartile range) of 1858 (703, 4094) words in their monitoring diary over the eight-week study period. Patients reported a variety of important life

changes due to their COAG, such as increased frustration and cessation of activities as well as stressing the importance of social support and clinician trust as protective factors for their wellbeing. These findings are interesting because they provide some evidence that anxiety (particularly around activities) and depression still affect patients who are in the latter stages of their disease process. Most patients found the monitoring exercise to be useful and felt that they would benefit from continuing to use self-monitoring diaries in the future. The content of the self-monitoring activity presented in this chapter incorporated elements of other interventions in eye disease literature, such as diaries to monitor emotional representations (Stanford, Waterman, Russell, & Harper, 2009) and monitoring of medication adherence (Newman-Casey, Weizer, Heisler, Lee, & Stein, 2013). This study also incorporated a measure of personality (Gosling, Rentfrow, & Swann, 2003) and found that patients' emotional stability was weakly correlated with uptake of the self-monitoring exercise ($rho=0.36$, $p<0.05$), which may have important implications. Particularly as one of the participants in the study identified that a constant focus on symptoms, lead to negative emotions over the study period. This could be an important finding to consider when designing self-monitoring exercises for patients in the future, as private self-focus and rumination is associated with depression and generalised anxiety in some people (Mor & Winquist, 2002). However, expression of negative emotions has been shown to lead to long-term habituation in others (de Ridder, Geenen, Kuijer, & van Middendorp, 2008). It is possible that this relationship may be mediated by personality factors, such as the ones measured in this study, but the small sample size and lack of

information on the validity of the self-monitoring exercise means that this idea needs to be investigated further.

Participants in **Chapter Three** identified social support as a key factor when contributing to their adjustment to illness and in forming successful illness behaviours. Therefore, the impact of supporting a patient with COAG on informal caregivers was investigated in **Chapter Four**. This was achieved through estimating ICG strain in COAG using a standardised instrument and comparing against estimates in other neurological illnesses. This study provided evidence that ICG strain in COAG really only becomes apparent when the patient is in the more advanced stages of the disease, and that it is much lower than ICG strain reported in other conditions such as Parkinson's Disease and Multiple Sclerosis (Peters, Jenkinson, Doll, Playford, & Fitzpatrick, 2013). Mean (standard deviation) caregiver strain was considerably inflated in the advanced patients (5.6 [4.9] vs 1.5 [2.2] for non-advanced; p=0.040). In the patients with an ICG, 87% (33/38) self-reported they were married or in a committed relationship as opposed to being single, divorced, widowed or separated; in contrast this proportion was 60% (40/67) in the patients who did not have an ICG and the difference was statistically significant (p=0.004). This indicates that the presence of an ICG is likely to be related to whether a patient is married or in a committed relationship. Participants in this study specifically identified ICG strain in the areas of work and emotional adjustments, changes to personal plans and changes in their personal relationship with the patient. These findings add to previous work which has suggested that ICGs for patients with COAG expressed concerns about the lack of patient education and

the development of poor coping mechanisms as a result (Shtein, Newman-Casey, Herndon, Coleman, & Lee, 2016; Waisbourd, et al., 2016). The study presented in **Chapter Four** provides evidence that ICG strain in COAG is related to worsening vision and QoL, but it does not take into consideration potential co-morbid conditions. This is important because previous studies have identified co-morbid conditions as potentially important indicators for the presence of an ICG in COAG (Read, et al., 2018). Interestingly, no differences were found in the levels of ICG strain experienced by men and women, which is in contrast to previous literature suggested that women were the most affected by this role (Yee & Schulz, 2000; McCullagh, Brigstocke, Donaldson, & Kalra, 2005). However, it was noted that the measure used to investigate ICG strain in this study (MCSI; Thornton & Travis, 2003) may not have been sensitive enough to capture condition specific strains.

Based on the findings of the study in **Chapter Four**, it was hypothesised that there may be COAG specific strains that formed part of the ICG experience in COAG. **Chapter Five** therefore aimed to investigate this idea further. Focus groups were conducted with two different groups and interpretative phenomenological analysis (IPA) was used to present an account of the participants' experiences of ICG in COAG. Participants without an ICG feared a loss of independence, whereas those with an ICG and their ICGs stressed collaboration where loss of independence became a problem. ICGs and the patients discussed the importance of the ICG being involved in communicating with care teams and administering medications, factors also identified as being protective to the patients' wellbeing the diary exercise presented in **Chapter Three**. In a clinical setting, it has been demonstrated that

having an ICG present can help improve doctor-patient communication, particularly during history taking, as the ICG is often able to provide more information than the patient (Laidsaar-Powell, et al., 2013) and the findings from this research indicate that this may be the case in COAG too. ICGs in the study felt a sense of obligation toward the patient, but this was not generally associated with negative emotions, except in one participant. The majority of ICGs reported changes to personal plans, for example to attend hospital appointments, and emotional adjustments during the focus group, but these were not generally negative. The findings of this study indicate that the estimate of ICG strain in **Chapter Four** may be capturing the experience of being an ICG, *rather than ICG strain*. This study speculates that a more integrated approach should be taken to COAG management in order to inform successful health behaviours for some patients. However, it is important to consider that this study may have been underpowered compared to the optimum number of participants for a focus groups study (Bowling & Ebrahim, 2005). It is likely that other factors may also influence the experience of being an ICG in COAG, such as personality and the ICGs perceived ability to successfully manage the condition (Lockenhoff, Duberstein, Friedman, & Costa Jr, 2011).

6.2 Future Work

The studies reported in this thesis provide some understanding of the cognitive and emotional processes involved in adjustment to and management of COAG. Yet, because they represent novel areas of study in COAG, they also raise a number of interesting questions, which should form the basis for future research in this area. Specific areas for future research are discussed in this section:

Chapter Two demonstrated that illness representations may be dynamic in COAG, but this study was performed as a case-control cross-sectional study, which only included participants at two clinical centres with a fairly homogenous patient group. This makes it hard to determine the effect of demographic characteristics on illness representations in the COAG population, and this should be taken into consideration in future research. A longitudinal cohort study examining a wider demographic of patients from different clinical centres would be useful for exploring these ideas. It may be particularly interesting to also include the idea of the instrumental social support network in COAG that was presented in **Chapters Three, Four and Five** in any cohort study. Previous research has demonstrated discordance between illness representations of caregivers and patients, with caregivers having notably more negative representations (Richardson, Morton, & Broadbent, 2015). The interaction between patient and caregiver illness representations was also found to have an effect on patient QoL and implications for care, so this is an important area for further investigation. A notable finding from the study in **Chapter Two** was the similarity between illness representations in patients with COAG and patients with

OHT. A study exploring, in more detail, self-reported outlook and prognosis (consequence beliefs) for people with OHT and how this differs from patients diagnosed with COAG with VF loss would be interesting. This could form part of a follow-up study to look at the impact of more detailed post diagnosis education in both COAG and OHT. Patients could be placed in different educational intervention groups to investigate how post diagnosis education impacts the formation and maintenance of illness representations. Previous research has identified nine key health education needs for COAG/OHT patients (Waterman, et al., 2013) and a study incorporating these may be useful as a basis for change surrounding the information delivered to patients with OHT at the point of diagnosis.

The work in **Chapter Three** posits the idea that self-monitoring visual and psychological status outside of clinic may be a useful tool for patients. Further work should investigate the usefulness and feasibility of a carefully designed self-monitoring intervention in a larger group of patients. This will also allow for better concsions to be formed around the impact of patient personality on engagement with self-monitoring interventions. The findings suggested that an online diary may yield more information about a patient's psychological wellbeing when compared to a hospital consultation and this should be investigated further by determining what, if any, insight patients provide clinicians with during consultations. A notable finding of the work in **Chapter Three** was that one of the ten participants felt that a constant focus on symptoms was damaging to their psychological wellbeing. This suggests that any further research into the idea of self-monitoring visual symptoms in COAG may benefit from the inclusion of aspects of positive psychology. Positive

psychology interventions have been shown to improve happiness, satisfaction and enhance patient motivation (Wood, Froh, & Geraghty, 2010). It may therefore be worthwhile to trial an intervention, which includes one or more aspects of the Action for Happiness 'Happiness Action Pack' (Action for Happiness, 2016). This work should also put a specific focus on targeting patients who may need extra psychological support because of a lack of perceived or actual social support.

The work in **Chapter Four** raised important questions about the nature of informal caregiving (ICG) in COAG. Caregivers identified work and emotional adjustments, changes to personal plans and changes in their relationship with the patient as key areas for concern. This was supported by the findings in **Chapter Five** where ICGs reported a sense of obligation toward the patient; particularly post operatively and with their daily medications. Although the ICGs in this study did not have particularly negative connotations with their caregiving role, it is important to raise awareness, as we know from previous research, that feelings toward the ICG role can affect the patient-ICG relationship in the long term (Vukicevic, Heraghty, Cummins, Gopinath, & Mitchell, 2016; Fingerman, Pitzer, Lefkowitz, Birditt, & Mroczek, 2008; Anderson & White, 2018). A raised awareness is also useful because there is evidence that ICGs who are given adequate support do not experience as much strain (Royal College of General Practitioners, 2012). The establishment of caregiver support groups in COAG would form an interesting topic for future research. There is evidence that caregiver support groups give ICGs the opportunity to seek guidance, information and encouragement (White & Dorman, 2000). These support groups need not be large face to face meetings, but could take the form of

telephone or internet groups, as there is evidence that these provide equally effective improvements in mood states and self-reported caregiver burden (Brown, et al., 1999). There is evidence that online caregiver support groups may be less egalitarian and less concerned with social status than face-to-face support groups, which could benefit those from disadvantaged backgrounds (White & Dorman, 2001).

Identifying and supporting ICGs in COAG is imperative, but more research should also be conducted on the role that ICGs may play, particularly in terms of contributions to hospital consultations and clinical decision making. The participants in **Chapter Five** reported that they found it extremely useful to have their ICG present during hospital consultations, and some participants who did not identify an ICG also reported that they found having a companion present during consultations was useful or would be useful. It may be important then to speak to clinicians about their experiences of what is deemed *triadic consultations.* Research evidence on this topic has diverse conclusions. A review of 52 studies on triadic consultations found that whilst some clinicians view ICGs as a useful tool for symptom monitoring and history taking, some view ICGs as problematic in hospital consultations (Laidsaar-Powell, et al., 2013). There may also be scope to conduct future research with clinicians using the TRIO guidelines to improve clinical communication if challenges arise with the presence of family ICGs (Laidsaar-Powell, Butow, Boyle, & Juraskova, 2018).

In **Chapter Five** there were differences between those who identified an ICG and those who did not and these may form an interesting basis for future work. Participants in the group that did not identify an ICG (Group A) still reported that they received help with instilling eye drops, particularly post-operatively and some reported that their partner attended their hospital appointments. This may be because the word 'caregiver' lacks consistent conceptualisation (Hermanns & Mastel-Smith, 2012). This again highlights the need for raised awareness around the ICG role in COAG. The largest difference between those with an ICG and those without was their emotional response to loss of independence. Participants in Group A repeatedly talked about the need to maintain independence, whereas this was not mentioned in Group B, where a more collaborative approach was taken. This highlights idiosyncratic strains for COAG patients that might include the psychological burden of having a potentially blinding condition or loss of visual function that might restrict mobility or remove a driving licence. It is notable that participants in **Chapter Five** framed their fears of going blind by reflecting on the experiences of others, which other studies have suggested may be a maladaptive coping mechanism employed to enhance short-term wellbeing (Weiss & Lang, 2012). However, in this population, eventual loss of sight may present larger psychological challenges. There is evidence that a strong illness identity, which may be absent in patients who do not identify with a COAG diagnosis, leads to acceptance of the diagnosis and better functional and psychological outcomes (Hale, Treharne, & Kitas, 2007; Kirby, Broom, Sibbritt, Refshauge, & Adams, 2015). This may in turn

affect the identity of their ICG, should they need one in the future (Eifert, Adams, Dudley, & Perko, 2015).

Others have discussed the importance of identifying a *precipice* when patients lose self-medicating capability, and this might be identifiable with an appropriate instrument for the ICG (Read, et al., 2018). Therefore, in future research the idea of the existence of a precipice of care should also be investigated in relation to other variables involved in the loss of independence in COAG, such as losing the ability drive.

6.3 Autobiographical Reflection

The importance of honest reflexivity when using qualitative methodology in social scientific research is widely acknowledged. This is the process of becoming self-aware and making an effort to consider your own thoughts and actions as a researcher, and how these may impact data collection or data analysis (Mills, Durepos, & Wiebe, 2010). As the author of this thesis, it is important for me to acknowledge my own position and the reflexive process that I employed when conducting the studies. At the beginning of my PhD, I was relatively new to qualitative data analysis, and found little guidance within the ophthalmology research community on methodological best practice. I believe that this may have influenced me to take a cautious approach to data analysis, particularly in **Chapter Three**, where I identified and presented only semantic (explicit) themes within the data. A trend within thematic analysis is to also present latent themes, which are based on underlying ideas or assumptions and go beyond the actual content of the data set (Braun & Clarke, 2006). Due to the lack of research on the topic of the patient experience in COAG, there were few existing assumptions to rely on and therefore only semantic themes were identified in the data. A more experienced qualitative researcher may have used theoretical assumptions from other chronic illnesses to make use of the latent aspects of the data. During the final year of my PhD, I was employed as a lecturer in health psychology, and became part of an academic community, which I *felt* placed a higher value on the findings of qualitative

research. This position also gave me access to experienced qualitative researchers and enabled me to build my skills in this area. For the research presented in **Chapter Five**, I employed a reflexive journal in order to assess the impact of my own questions and experiences regarding caregiving in COAG. A certain degree of expectation existed when I initially began reading the data set, which was due to the findings of the work presented in **Chapter Four**. The use of interpretative phenomenological analysis (IPA) in this study was key to minimising the impact of these assumptions on the data analysis. IPA is challenging, as the researcher must interpret the experiences of another individual in real terms. Smith and Osborn (2012) describe the process as, 'the researcher trying to make sense of the participants trying to make sense of their world'. In this way, IPA is more of a descriptive tool rather than an analytical one. The use of the reflexive journal minimised the possibility that I was not going beyond what existed within the data set or making assumptions about participant experiences. These reflections are important when making conclusions based on the qualitative analyses conducted within this thesis.

6.4 Final word

The material presented within this thesis provides an overview of the complex emotional and cognitive processes involved in adaptation to COAG as a chronic illness. The work demonstrates that living with COAG is a dynamic process, involving both the patient and their informal caregivers. This thesis highlights the need for more work investigating the cognitive and emotional processes of patients with COAG. There is also a need to investigate the role of the clinical team in adapting to COAG, with the view to providing a more integrated, multifaceted approach to clinical care in COAG.

List of Supporting Publications

Peer reviewed manuscripts

McDonald, L., Glen, F. C., Taylor, D. J. & Crabb, D., P. (2017) Self-Monitoring Symptoms in Glaucoma: A Feasibility Study of a Web-Based Diary Tool. *Journal of Ophthalmology.* Article ID: 8452840. 8 pages. https://doi.org/10.1155/2017/8452840

McDonald, L., Boodhna, T., Ajtony, C., Turnbull, P., Bourne, R. R. A. & Crabb, D. P. (2019) Illness Perceptions in People Newly Diagnosed with Glaucoma and Ocular Hypertension. *British Journal of Ophthalmology.* http://dx.doi.org/10.1136/bjophthalmol-2018-313781

McDonald, L., Chang, L., Turnbull, P. & Crabb D.P. (2020) Taking the strain? The impact of glaucoma on patient's informal caregivers. *Eye*. 34. 197-204. https://doi.org/10.1038/s41433-019-0688-4

Conference presentations

United Kingdom and Éire Glaucoma Society (UKÉGS) – City, University of London 2018 – London, England – Poster Presentation

Taking the strain? The impact of glaucoma on patient's informal caregivers.

***Leanne McDonald**, Lydia Chang, Paula Turnbull, David P. Crabb*

British Congress of Optometry and Vision Science (BCOVS) – Anglia Ruskin University 2018 – Cambridge, England – Oral Presentation

Taking the strain? The impact of glaucoma on patient's informal caregivers.

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Illness Perceptions in People Newly Diagnosed with Glaucoma and Ocular Hypertension.

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Self-Monitoring Symptoms in Glaucoma: A Feasibility Study of a Web-Based Diary Tool

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The Association of Research in Vision and Ophthalmology (ARVO) 2016 – Seattle, Washington, USA – Poster Presentation

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References

Aaronson, N. K. (1988). Quantitative issues in health-related quality of life assessment. *Health Policy, 10*(3), 217-230.

Action for Happiness. (2016). *Action For Happiness: Happiness Action Pack.* Retrieved from Action For Happiness: https://www.actionforhappiness.org/media/80216/happiness_action_pack.pdf

Alqudah, A., Mansberger, S. L., Gardiner, S. K., & Demirel, S. (2016). Vision-related quality of life in glaucoma suspect or early glaucoma patients. *Journal of Glaucoma*, 629-633.

Altangerel, U., Spaeth, G. L., & Steinmann, W. C. (2006). Assessment of function related to vision (AFREV). *Ophthalmic Epidemiology*, 67-80.

Anderson, E. Q., & White, K. M. (2018). "It Has Changed My Life": An Exploration of Caregiver Experiences in Serious Illness. *The American Journal of Hospice and Palliative Care, 35*(2), 266-274.

Applebaum, A. J., Stein, E. M., Lord-Bessen, J., Pessin, H., Rosenfeld, B., & Breitbart, W. (2014). Optimism, Social Support, and Mental Health Outcomes in Patients with Advanced Cancer. *Psychooncology*, 299-306.

Araci, I. E., Su, B., Quake, S. R., & Mandel, Y. (2014). An implantable microfluidic device for self-monitoring of intraocular pressure. *Nature Medicine, 20*(9), 1074-1078.

Ariza-Vega, P., Ortiz-Pina, M., Kristensen, M. T., Castellote-Caballero, Y., & Jimenez-Moleon, J. J. (2019). High perceived caregiver burden for relatives of patients following hip fracture surgery. *Disability and Rehabilitation, 41*(3), 311-318.

Asaoka, R., Crabb, D. P., Yamashita, T., Russell, R. A., Wang, Y. X., & Garway-Heath, D. F. (2011). Patients Have Two Eyes!: Binocular versus Better Eye Visual Field Indices. *Investigative Ophthalmology and Visual Science, 52*(9), 7007-7011.

Asch, D., Muller, R., & Volpp, K. (2012). Automated hovering in healthcare – watching over the 5000 hours,. *The New England Journal of Medicine, 367*(1), 1-3.

Asoaka, R. (2013). The relationship between visual acuity and central visual field sensitivity in advanced glaucoma. *British Journal of Ophthalmology*, 1355-1356.

Austenfeld, J. L., & Stanton, A. L. (2004). Coping through emotional approach: a new look at emotion, coping, and health-related outcomes. *Journal of Personality, 72*(6), 1335-1363.

Baker, C., & Stern, P. N. (1993). Finding meaning in chronic illness is key to self-care. *The Canadian Journal of Nursing Research*, 23-36.

Bandura, A., & Adams, N. E. (1977). Analysis of self-efficacy theory of behavioral change. *Cognitive Therapy and Research*, 287-310.

Banerjee, S. (2015). Multimorbidity—older adults need health care that can count past one. *The Lancet, 385*(9968), 587-589.

Barlow, J., Wright, C., Sheasby, J., Turner, A., & Hainsworth, J. (2002). Self-management approaches for people with chronic conditions: a review. *Patient Education and Counselling*, 177-187.

Barnett, K., Mercer, S. W., Norbury, M., Watt, G., Wyke, S., & Guthrie, B. (2012). Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross sectional study. *The Lancet, 380*, 37-43.

Basch, E., Deal, A. M., Kris, M. G., Scher, H. I., Hudis, C. A., Sabbatini, P., . . . Schrag, D. (2016). Symptom Monitoring With Patient-Reported Outcomes During Routine Cancer Treatment: A Randomized Controlled Trial. *Journal of Clinial Oncology, 34*(6), 557-565.

Batcheller, L., & Baker, D. (2019). Cost of disease modifying therapies for multiple sclerosis: Is front-loading the answer? *Journal of the Neurological Sciences, 404*(15), 19-28.

Bell, R. W., & O'Brien, C. (1997). Accuracy of referral to a glaucoma clinic. *Opthalmic and Physiological Optics, 17*(1), 7-11.

Bernell, S., & Howard, S. W. (2016). Use Your Words Carefully: What Is a Chronic Disease? *Frontiers in Public Health, 4*, 159.

Bhargava, J. S., Bhan-Bhargava, A., Foss, A. J., & King, A. J. (2008). Views of glaucoma patients on provision of follow-up care; an assessment of patient preferences by conjoint analysis. *British Journal of Ophthalmology, 92*(12), 1601-1605.

Biggerstaff, D., & Thompson, A. R. (2005). Interpretive phenomenological analysis (IPA): a qualitative methodology of choice in health care research. *Qualitative Research in Psychology, 5*, 214-224. doi:http://dx.doi.org/10.1080/14780880802314304

Bodenheimer, T., Lorig, K., & Holman, H. (2002). Patient self-management of chronic disease in primary care. *Journal of the American Medical Association*, 2469-2475.

Boland, M. V., Chang, D. S., Frazier, T., Plyer, R., Jefferys, J. L., & Friedman, D. S. (2014). Automated telecommunication-based reminders and adherence with once-daily glaucoma medication dosing: the automated dosing reminder study. *JAMA Ophthalmology, 132*(7), 845-850.

Boodhna, T., & Crabb, D. P. (2016). More frequent, more costly? Health economic modelling aspects of monitoring glaucoma patients in England. *BMC Health Services Research, 16*(1), 611.

Borgermans, L., & Devroey, D. (2017). A Policy Guide on Integrated Care (PGIC): Lessons Learned from EU Project INTEGRATE and Beyond. *International Journal of Integrated Care, 17*(4), 8. doi:http://doi.org/10.5334/ijic.3295

Bourne, R. R., Jonas, J. B., Bron, A. M., Cicinelli, M. V., Das, A., Flaxman, S. R., . . . Resnikoff, S. (2018). Prevalence and causes of vision loss in high-income countries and in Eastern

and Central Europe in 2015: magnitude, temporal trends and projections. *British Journal of Ophthalmology, 102*(5), 575-585.

Bowling, A., & Ebrahim, S. (2005). *Handbook of health research methods. Investigation, measurement and analysis.* Maidenhead. UK.: Open University Press.

Boyd, K. (2019, March 27). *What is Gonioscopy?* Retrieved from American Academy of Ophthalmology: https://www.aao.org/eye-health/treatments/what-is-gonioscopy

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101.

Brenes, G. A. (2003). Anxiety and chronic obstructive pulmonary disease: prevalence, impact and treatment,. *Psychosomatic Disorders, 65*(6), 963-970.

Brisenden, S. (1986). Independent Living and the Medical Model of Disability. *Disability, Handicap & Society, 1*(2), 173-178. doi:https://doi.org/10.1080/02674648666780171

Broadbent, E., Petrie, K. J., & Main, J. (2006). The Brief Illness Perception Questionnaire. *Journal of Psychosomatic Research, 60*, 631-637.

Broadbent, E., Wilkes, C., & Koschwanez, H. (2015). A systematic review and meta-analysis of the Brief Illness Perception Questionnaire. *Psychology and Health, 30*, 1361-1385.

Brody, B. L., Roch-Levecq, A., Gamst, A. C., Maclean, K., Kaplan, R. M., & Brown, S. I. (2002). Self-management of Age-Related Macular Degeneration and Quality of Life: A Randomized Controlled Trial. *Archives of Ophthalmology, 120*(11), 1477-1483. doi:doi:10.1001/archopht.120.11.1477

Brown, G. C., Brown, M. M., & Sharma, S. (2000). Difference between ophthalmologists' and patients' perceptions of quality of life associated with age-related macular degeneration. *Canadian Journal of Ophthalmology, 35*(3), 127-133.

Brown, R., Pain, K., Berwald, C., Hirschi, P., Delehanty, R., & Miller, H. (1999). Distance Education and Caregiver Support Groups: Comparison of Traditional and Telephone Groups. *Head Trauma Rehabilition, 14*(3), 257-268.

Burleson Sullivan, A., & Miller, D. (2015). Who is taking care of the caregiver? *Journal of Patient Experience, 2*(1), 7-12.

Burmedi, D., Becker, S., Heyl, V., Wahl, H.-W., & Himmselsbach, I. (2009). Emotional and social consequences of age-related low vision. *Visual Impairment Research*, 47-71. doi:https://doi.org/10.1076/vimr.4.1.47.15634

Caplan, S., & Whittemore, R. (2013). Barriers to Treatment Engagement for Depression among Latinas. *Issues in Mental Health Nursing, 34*, 412-424.

Carnethon, M. R. (2009). Physical activity and cardiovascular disease: how much is enough? *American Journal of Lifestyle Medicine*, 44-49.

Carr, A. J., Gibson, B., & Robinson, P. G. (2001). Is quality of life determined by expectations or experience? *British Medical Journal, 322*(7296), 1240-1243.

Casson, R. J., Chidlow, G., Wood, J. P., Crowston, J. G., & Goldberg, I. (2012). Definition of glaucoma: clinical and experimental concepts. *Clinical and Experimental Ophthalmology, 40*(4), 341-349.

Chan, E. W., Chiang, P. P., Liao, J., Rees, G., Wong, T. Y., Lam, J. S., . . . Lamoureux, E. (2015). Glaucoma and associated visual acuity and field loss significantly affect glaucoma-specific psychosocial functioning. *Ophthalmology*, 494-501.

Chan, M. P., Broadway, D. C., Khawaja, A. P., Yip, J. L., Garway-Heath, D. F., Burr, J. M., . . . Foster, P. J. (2017). Glaucoma and intraocular pressure in EPIC-Norfolk Eye Study: cross sectional study. *British Medical Journal*, 358.

Chang, S., Zhang, Y., Jeyagurunathan, A., Lau, Y. W., Sagayadevan, V., Chong, S. A., & Subramaniam, M. (2016). Providing care to relatives with mental illness: reactions and distress among primary informal caregivers. *BMC Psychiatry, 16*, 80.

Chen, S. L., Tsai, J. C., & Chou, K. R. (2011). Illness perceptions and adherence to therapeutic regimens among patients with hypertension: a structural modelling approach. *International Journal of Nursing Studies, 48*, 235-245.

Clare, L., Quinn, C., Jones, I. R., & Woods, R. T. (2016). "I Don't Think Of It As An Illness": Illness Representations in Mild to Moderate Dementia. *Journal of Alzheimer's Disease, 51*(1), 139-150.

Coleman, A. L., & Miglior, S. (2008). Risk factors for glaucoma onset and progression. *Survey of Opthalmology, 53*(1), S3-10.

Connidis, I. A., & McMullin, J. A. (2002). Sociological Ambivalence and Family Ties: A Critical Perspective. *Journal of Marriage and Family, 64*(3), 558-567.

Crabb, D. P. (2016). A view on glaucoma - are we seeing it clearly? *Eye (Lond), 30*(2), 304-313.

Crabb, D. P., Fitzke, F. W., & Hitchings, R. A. (2004). A practical approach to measuring the visual field component of fitness to drive. *British Journal of Ophthalmology, 88*, 1191-1196.

Crabb, D. P., Saunders, L. J., & Edwards, L. A. (2017). Cases of advanced visual field loss at referral to glaucoma clinics – more men than women? *Ophthalmic and Physiological Optics, 37*(1), 82-87.

Crabb, D. P., Smith, N. D., Glen, F. C., Burton, R., & Garway-Heath, D. F. (2013). How does glaucoma look? *Ophthalmology*, 1120-1126.

Curtin , R. B., Walters, B. A., Schatell, D., Pennell, P., Wise, M., & Klicko, K. (2008). Self-efficacy and self-management behaviors in patients with chronic kidney disease. *Advances in Chronic Kidney Disease*, 191-205.

Damji, K. F., Bovell, A. M., Hodge, W. G., Buhrmann, Y., Shah, K., Buhrmann, R., & Pan, Y. I. (2006). Selective laser trabeculoplasty versus argon laser trabeculoplasty: results from a 1-year randomised clinical trial. *British Journal of Ophthalmology, 90*, 1490-1494.

Damman, W., Liu, R., Kaptein, A. A., Evers, A. W., van Middendorp, H., Rosendaal, F. R., & Kloppenburg, M. (2018). Illness perceptions and their association with 2 year functional status and change in patients with hand osteoarthritis. *Rheumatology, 57*(2), 2190-2199.

de Ridder, D., Geenen, R., Kuijer, R., & van Middendorp, H. (2008). Psychological adjustment to chronic disease. *The Lancet, 372*(9634), 19-25.

Delaney, M., Simpson, J., & Leroi, I. (2011). Perceptions of causeand control of impulse control behaviours in people with Parkinson's disease. *British Journal of Health Psychology*, 522-535.

Denollet, J. (2000). Type D Personality: A potential risk factor refined. *Journal of Psychosomatic Research, 49*, 255-266.

Devlin, N. J., & Appleby, J. (2010). *Getting the most out of PROMs: Putting health outcomes at the heart of NHS decision making.* London: King's Fund.

Devlin, N., & Brooks, R. (2017). EQ-5D and the EuroQol Group: Past, Present and Future. *Applied Health Economics and Health Policy, 15*, 127-137.

Dew, K., Morgan, S., Dowell, A., Bushnell, J., & Collings, S. (2007). 'It puts things out of your control': fear of consequences as a barrier to patient disclosure of mental health issues to general practitioners. *Sociology of Health and Illness, 29*(7), 1059-1074.

Division of Mental Health and Prevention of Substance Abuse. (1997). *WHOQOL Measuring Quality of Life.* Geneva: World Health Organization.

Eastwood, C. A., Travis, L., Morgenstern, T. T., & Donaho, E. K. (2007). Weight and Symptom Diary for Self-monitoring in Heart Failure Clinic Patients. *The Journal of Cardiovascular Nursing, 22*(5), 382-389.

Eifert, E. K., Adams, R., Dudley, W., & Perko, M. (2015). Family Caregiver Identity: A Literature Review. *American Journal of Health Education, 46*(6), 357-367.

Ellingson, L. L. (2002). The roles of companions in geriatric patient-interdisciplinary oncology team interactions. *Journal of Aging Studies, 16*, 361-382.

EuroQol. (1990). EuroQol - a new facility for the measurement of health-related quality of life. *Health Policy, 16*, 199-208.

Falvo, D. (2005). Psychosocial and Functional Aspects of Chronic Illness and Disability. In D. Falvo, *Medical and Psychosocial Aspects of Chronic Illness and Disability* (p. 1). London, UK: Jones and Bartlett Publishers International.

Farmer, A., Gibson, O. J., Tarassenko, L., & Neil, A. (2005). A systematic review of telemedicine interventions to support blood glucose self-monitoring in diabetes. *Diabetic Medicine, 22*(10), 1372-1378.

Feinstein, L., Sabates, R., Anderson, T. M., Sorhaindo, A., & Hammond, C. (2006). *What are the effects of education on health?* London: OECD.

Fenwick, E. K., Ong, P. G., Eyn Kidd Man, R., Cheng, C. Y., Sabanayagam, C., Wong, T. Y., & Lamoureux, E. L. (2016). Association of Vision Impairment and Major Eye Diseases. *JAMA Ophthalmology, 134*(10), 1087-1093.

Ferris, F. L., Kassoff, A., Bresnick, G. H., Bailey, I. (1982) New visual acuity charts for clinical research. *American Journal of Ophthalmology, 94*(1), 91-96.

Fingerman, K. L., Pitzer, L., Lefkowitz, E. S., Birditt, K. S., & Mroczek, D. (2008). Ambivalent Relationship Qualities Between Adults and Their Parents: Implications for the Wellbeing of Both Parties. *The Journals of Gerontology: Series B, 63*(6), 362-371.

French, D., Cooper, A., & Weinman, J. (2006). Illness perceptions predict attendance at cardiac rehabilitation following acute myocardial infarction: A systematic review with meta-analysis. *Journal of Psychosomatic Research, 61*(6), 757-767.

Friedman, D. S., Hahn, S. R., & Gelb, L. (2008). Doctor-patient communication, health-related beliefs, and adherence in glaucoma: results from the glaucoma adherence and persistency study. *Ophthalmology, 115*, 1320-1327.

Friedman, D. S., Hahn, S. R., Quigley, H. A., Kotak, S., Kim, E., Onofrey, M., . . . Mardekian, J. (2009). Doctor–Patient Communication in Glaucoma Care: Analysis of Videotaped Encounters in Community-Based Office Practice. *Ophthalmology, 116*(12), 2277-2285.

Frostholm, L., Oernboel, E., Christensen, K. S., Toft, T., Olesen, F., Weinman, J., & Fink, P. (2007). Do illness perceptions predict health outcomes in primary care patients? A 2-year follow-up study. *Journal of Psychosomatic Research, 62*(2), 129-138.

Furnham, A. (1989). Personality correlates of self-monitoring: The relationship between extraversion, neuroticism, type a behaviour and Snyder's self-monitoring construct. *Personality and Individual Differences, 10*(1), 35-42.

Gaasterland, D. E., Blackwell, B., Dally, L. G., Caprioli, J., Katz, L. J., Ederer, F., & Investigators, A. G. (2001). The Advanced Glaucoma Intervention Study (AGIS): 10. Variability among academic glaucoma subspecialists in assessing optic disc notching. *Transactions of the American Ophthalamological Society, 99*, 177-184.

Gazzard, G., Konstantakopoulou, E., Garway-Heath, D., Garg, A., Vickerstaff, V., Hunter, R., . . . LiGHT Trial Study Group. (2019). Selective laser trabeculoplasty versus eye drops for first-line treatment of ocular hypertension and glaucoma (LiGHT): a multicentre randomised controlled trial. *The Lancet, 393*, 1505-1516.

Geruschat, D. R., & Turano, K. A. (2007). Estimating the Amount of Mental Effort Required for Independent Mobility: Persons with Glaucoma. *Investigative Ophthalmology and Visual Science*, 3988-3994.

Gillespie-Gallery, H., Subramanian, A., & Conway, M. L. (2013). Micro-costing the provision of emotional support and information in UK eye clinics. *BMC Health Services Research, 13*, 482.

Glaucoma in Perspective UK on the App Store. (2019, August 21). Retrieved from App Store: https://itunes.apple.com/gb/app/glaucoma-in-perspective-uk/id991094773?mt=8.

Glen, F. C., & Crabb, D. P. (2015). Living with glaucoma: a qualitative study of functional implications and patients' coping behaviours. *BMC Ophthalmology, 15*, 128.

Glen, F. C., Crabb, D. P., & Garway-Heath, D. F. (2011). The direction of research into visual disability and quality of life in glaucoma. *BMC Ophthalmology*, 11-19.

Glen, F. C., Crabb, D. P., Smith, N. D., Burton, R., & Garway-Heath, D. F. (2012). Do patients with glaucoma have difficulty recognizing faces? *Investigative Ophthalmology and Visual Science*, 3629-3637.

Glen, F. C., Smith, N. D., & Crabb, D. P. (2013). Saccadic eye movements and face recognition performance in patients with central glaucomatous visual field defects. *Vision Research*, 42-51.

Gohil, R., Crosby-Nwaobi, R., Forbes, A., Burton, B., Hykin, P., & Sivaprasad, S. (2015). Caregiver burden in patients recieving Ranibizumab therapy for neovascular macular degeneration. *PLOS One, 10*(6), e0129361.

Goldberg, I., Clement, C. I., Chiang, T. H., Walt, J. G., Lee, L. J., Graham, S., & Healey, P. (2009). Assessing Quality of Life in Patients With Glaucoma Using the Glaucoma Quality of Life-15 (GQL-15) Questionnaire. *Journal of Glaucoma*, 6-12.

Gopinath, B., Craig , A., Kifley, A., Liew, G., Bloffwitch, J., Van Vu, K., . . . Mitchell, P. (2017). Implementing a multi-modal support service model for the family caregivers of persons with age-related macular degeneration: a study protocol for a randomised controlled trial . *BMJ Open, 7*(8), e018204.

Gordon, M. O., Beiser, J. A., & Brandt, J. D. (2002). The ocular hypertension treatment study: baseline factors that predict the onset of primary open-angle glaucoma. *Archives of Ophthalmology, 120*, 714-720.

Gosling, S. D., Rentfrow, P. J., & Swann, W. B. (2003). A very brief measure of the big five personality domains. *Journal of Research in Personality, 37*(6), 504-528.

Gothwal, K., Bharani, S., & Mandal, A. K. (2015). Glaucoma Quality of Life of Caregivers of Children With Congenital Glaucoma : Development and Validation of a Novel Questionnaire (CarCGQoL) Vijaya. *Investigative Ophthalmology and Visual Science, 56*(1), 770-777.

Gray, T. A., Fenerty, C., Harper, R., Spencer, A. F., Campbell, M., Henson, D. B., & Waterman, H. (2012). Individualised patient care as an adjunct to standard care for promoting adherence to ocular hypotensive therapy: an exploratory randomised controlled trial. *Eye (Lond), 26*(3), 407-417.

Guo, L., Moss, S. E., Alexander, R. A., Ali, R. R., Fitzke, F. W., & Cordeiro, M. F. (2008). Retinal Ganglion Cell Apoptosis in Glaucoma Is Related to Intraocular Pressure and IOP-Induced Effects on Extracellular Matrix. *Investigative Opthalmology and Visual Science, 46*(1), 175-182.

Hagger, M. S., & Orbell, S. (2003). A meta-analytic review of the common-sense model of illness representations. *Psychology and Health, 18*(2), 141-184.

Hale, E. D., Treharne, G. J., & Kitas, G. D. (2007). The common-sense model of self-regulation of health and illness: how can we use it to understand and respond to our patients' needs? *Rheumatology*, 904-906.

Haley, W. E., Roth, D. L., Howard, G., & Safford, M. M. (2010). Caregiving Strain and Estimated Risk for Stroke and Coronary Heart Disease Among Spouse Caregivers. Differential Effects by Race and Sex. *Stroke, 41*(1), 331-336.

Halm, E. A., Mora, P., & Leventhal, H. (2006). No symptoms, no asthma: the acute episodic disease belief is associated with poor self-management among inner-city adults with persistent asthma. *Chest, 129*(3), 573-580.

Hanemoto, T., Hikichi, Y., Kikuci, N., & Kozawa, T. (2017). The impact of different anti-vascular endothelial growth factor treatment regimens on reducing burden for caregivers and patients with wet age-related macular degeneration in a single-center real-world Japanese setting. *PLoS ONE, 12*(12), e0189035 .

Hartman, S. J., Marinac, C. R., Belletierre, J., Godbole, S., Natarajan, L., Patterson, R. E., & Kerr, J. (2017). Objectively measured sedentary behavior and quality of life among survivors of early stage breast cancer. *Supportive Cancer Care*, 2495-2503.

Hartmann, C. W., & Rhee, D. J. (2006). The patients' journey: glaucoma. *British Medical Journal, 333*, 738-739.

Hassell, J. B., Lamoureux, E. L., & Keeffe, J. E. (2006). Impact of age related macular degeneration on quality of life. *British Journal of Ophthalmology*, 593-596.

Heffernan, E., Coulson, N. S., Henshaw, H., & Barry, J. G. (2016). Understanding the psychosocial experiences of adults with mild-moderate hearing loss: An application of Leventhal's self-regulatory model. *International Journal of Audiology, 55*(3), 1-10. doi:https://www.researchgate.net/deref/http%3A%2F%2Fwww.tandfonline.com%2Faction%2FshowCitFormats%3Fdoi%3D10.3109%2F14992027.2015.1117663

Heijl, A., Bengtsson, B., & Oskarsdottir, S. E. (2013). Prevalence and severity of undetected manifest glaucoma. Results from the Early Manifest Glaucoma Trial screening. *Opthalmology, 120*(8).

Heijmans, M. J. (1998). Coping and adaptive outcome in chronic fatigue syndrome: Importance of illness cognitions. *Journal of Psychosomatic Research*, 39-51.

Hemphill, R. C., Stephens, M. A., Rook, K. S., Franks, M. M., & Salem, J. K. (2013). Older adults' beliefs about the timeline of type 2 diabetes and adherence to dietary regimens. *Psychol Health*, 139-153.

Henson, D, B., Chaudry, S., Artes, P. H., Faragher, E. B., & Ansons, A. (2000). Response Variability in the Visual Field: Comparison of Optic Neuritis, Glaucoma, Ocular Hypertension and Normal Eyes. *Investigative Ophthalmology and Visual Science, 41,* 417-421.

Hermanns, M. L., & Mastel-Smith, B. A. (2012). Caregiving: A Qualitative Concept Analysis.

Holmes, M. (2010). A study to investigate the reliability and validity of the Ten-Item Personality Inventory, when compared with two robust inventories, within a British sample,. *Manchester Metropolitan University Psychology Journal, 6*, http://e-space.mmu.ac.uk/576699/.

Horne, R., & Weinman, J. (2002). Self-regulation and self-management in asthma: exploring the role of illness perceptions and treatment beliefs in explaining non-adherence to preventer medication. *Psychology and Health, 1*, 17-32.

Horowitz, A., Reinhardt, J., & Kennedy, G. (2005). Major and subthreshold depression among older adults seeking vision rehabilitation services. *American Journal of Geriatric Psychiatry, 13*(3), 180-187.

Hsiao, C. Y., Chang, C., & Chen, C. D. (2012). An investigation on illness perception and adherence among hypertensive patients. *The Kaohsiung Journal of Medical Sciences, 28*(8), 442-447.

Hsu, T., Loscalzo, M., Ramani, R., Forman, S., Popplewell, L., Clark, K., . . . Hurria, A. (2017). Are Disagreements in Caregiver and Patient Assessment of Patient Health Associated with Increased Caregiver Burden in Caregivers of Older Adults with Cancer? *Oncologist, 22*(11), 1383-1391.

Hu, F. B. (2003). Sedentary lifestyle and risk of obesity and type 2 diabetes. *Lipids*, 103-108.

Jacoby, W. G. (2000). Loess: a non-parametric graphical tool for depicting relationships between variables. *Electoral Studies, 19*(4), 577-613.

Jampel, H. D., Frick, K. D., Janz, N. K., Wren, P. A., Musch, D. C., Rimal, R., . . . Group, C. S. (2007). Depression and mood indicators in newly diagnosed glaucoma patients. *American Journal of Ophthalmology, 144*(2), 238-244.

Janz, N. K., Wren, P. A., Guire, K. E., Musch, D. C., Gillespie, B. W., Lichter, P. R., & Collaborative Initial Glaucoma Treatment Study. (2007). Fear of blindness in the Collaborative Initial Glaucoma Treatment Study: patterns and correlates over time. *Ophthalmology*, 2213-2220.

Janz, N. K., Wren, P. A., Lichter, P. R., Musch, D. C., Gillespie, B. W., & Guire, K. E. (2001). Quality of life in newly diagnosed glaucoma patients: The Collaborative Initial Glaucoma Treatment Study. *Ophthalmology, 108*(5), 887-897.

Jensen, M. P., Turner, J. A., & Romano, J. M. (1991). Self-efficacy and outcome expectancies: relationship to chronic pain coping strategies and adjustment. *Pain, 44*(3), 263-269.

Jones, L., Bryan, S. R., & Crabb, D. P. (2017). Gradually Then Suddenly? Decline in Vision-Related Quality of Life as Glaucoma Worsens. *Journal of Opthalmology, 2017*, 7 Pages.

Jones, L., Garway-Heath, D. F., Azuara-Blanco, A., Crabb, D. P., & Investigators, U. K. (2019). Are Patient Self-Reported Outcome Measures Sensitive Enough to Be Used as End Points in Clinical Trials?: Evidence from the United Kingdom Glaucoma Treatment Study. *Ophthalmology, 126*(5), 682-689.

Kantipuly, A., Pillai, M. R., Shroff, S., Khatiwala, R., Raman, G. V., Krishnadas, S. R., . . . Ehrlich, J. R. (2019). Caregiver Burden in Primary Congenital Glaucoma. *American Journal of Ophthalmology*.

Keeffe, J. E., Chou, S. L., & Lamoureux, E. L. (2009). The Cost of Care for People With Impaired Vision in Australia. *Archives of Ophthalmology, 127*(10), 1377-1381.

Kennedy, B. M., Jaligam, V., Conish, B. K., Johnson, W. D., Melancon, B., & Katzmarzyk, P. T. (2017). Exploring Patient, Caregiver, and Healthcare Provider Perceptions of Caring for Patients With Heart Failure: What Are the Implications? *The Ochsner Journal* , 93-102.

Kerr, C., Bottomley, C., Shingler, S., Giangregorio, L., de Freitas, H. M., Patel, C., . . . Gold, D. T. (2017). The importance of physical function to people with osteoporosis. *Osteoporosis International, 28*(5), 1597-1607.

Kerr, N. M., Wang, J., & Barton, K. (2017). Minimally invasive glaucoma surgery as primary stand-alone surgery for glaucoma. *Clinical and Experimental Ophthalmology, 45*(4), 393-400.

Khaw, P. T., Sherwood, M. B., Doyle, W., Smith, F., Grierson, I., McGorray, S., & Schultz, G. S. (1992). Intraoperative and post operative treatment with 5-Fluorouracil and mitomycin-c: long term effects in vivo on subconjunctival and scleral fibroblasts. *International Ophthalmology, 16*(4-5), 381-385.

Kim, Y., Pavlish, C., & Evangelista, L. S. (2012). Racial/ethnic differences in illness perceptions in minority patients undergoing maintenance haemodialysis. *Nephrology Nursing Journal, 39*, 39-49.

King, A., Azuara-Blanco, A., & Tuulonen, A. (2013). Glaucoma. *British Medical Journal, 346*.

Kirby, E., Broom, A., Sibbritt, D., Refshauge, K., & Adams, J. (2015). Suffering, recognition and reframing: Healthcare choices and plural care pathways for women with chronic back pain. *Current Sociology*, 1-17.

Kobak, K. (2001). *Patient Reactions to Computer Interviews*. Retrieved from Healthcare Technology Systems: http://www.healthtechsys.com/pdf/hts-209-patient_reactions_white_paper.pdf.

Kotowski, J., Wollstein, G., Ishikawa, H., & Schuman, J. S. (2014). Imaging of the Optic Nerve and Retinal Nerve Fiber Layer: an Essential Part of Glaucoma Diagnosis and Monitoring. *Survey of Ophthalmology, 59*(4), 458-467.

Lacey, J., Cate, H., & Broadway, D. C. (2009). Barriers to adherence with glaucoma medications: a qualitative research study. *Eye, 23*, 924-932.

Laidsaar-Powell, R. C., Butow, P. N., Bu, S., Charles, C., Gafni, A., Lam, W. W., . . . Juraskova, I. (2013). Physician–patient–companion communication and decision-making: A systematic review of triadic medical consultations. *Patient Education and Counselin, 91*(1), 3-13.

Laidsaar-Powell, R., Butow, P., Boyle, F., & Juraskova, I. (2018). Managing challenging interactions with family caregivers in the cancer setting: Guidelines for clinicians (TRIO Guidelines-2). *Patient Education and Counseling, 101*(6), 983-994.

Lamoureux, E., Hassell, J., & Keefe, J. (2004). The impact of diabetic retinopathy on participation in daily living. *Archives of Ophthalmology, 122*(1), 84-88.

Lawrenson, J. (2013). Glaucoma: the challenge of early case detection. *Ophthalmic and Physiological Optics, 33*(1), 3-6.

Lee, D. A., & Higginbotham, E. (2005). Glaucoma and its treatment: a review. *American Journal of Health-System Pharmacy, 62*(7), 691-699.

Lee, Y. H., Kim, C. S., & Hong, S. P. (2004). Rate of visual field progression in primary open-angle glaucoma and primary angle-closure glaucoma. *Korean Journal of Ophthalmology*, 106-115.

Leventhal, H., Brissette, I., Leventhal, E. A., Cameron, L. D., & Leventhal, H. (2003). *The Self-Regulation of Health and Illness.* London: Routledge.

Leventhal, H., Meyer, D., Nerenz, D. R., & Rachman, S. (1980). *The common sense representation of illness danger.* New York: Pergamon Press.

Li, N., Chen, X. M., Zhou, Y., Wei, M. L., & Yao, X. (2006). Travoprost compared with other prostaglandin analogues or timolol in patients with open-angle glaucoma or ocular hypertension: meta-analysis of randomized controlled trials. *Clinical and Experimental Ophthalmology, 34*(8), 755-764.

Llewellyn, C. D., McGurk, M., & Weinman, J. (2007). Illness and treatment beliefs in head and neck cancer: Is Leventhal's common sense model a useful framework for determining changes in outcomes over time? *Journal of Psychosomatic Research*, 17-26.

Lockenhoff, C. E., Duberstein, P. R., Friedman, B., & Costa Jr, P. T. (2011). Five-factor personality traits and subjective health among caregivers: the role of caregiver strain and self-efficacy. *Psychology and Aging, 26*(3), 592-604.

Longworth, L., Yang, Y., Young, T., Mulhern, B., Hernandez-Alava, M., Mukuria, C., . . . Brazier, J. (2014). Use of generic and condition-specific measures of health-related quality of life in NICE decision-making: a systematic review, statistical modelling and survey. *Health Technology Assessment, 18*(9), 1-224.

Lorig, K. R., Sobel, D. S., Ritter, P. L., Laurent, D., & Hobbs, M. (2001). Effect of a self-management program on patients with chronic disease. *Effective Clinical Practice*, 256-262.

Lorig, K., & Holman, H. (2003). Self-Management Education: History, Definition, Outcomes, and Mechanisms. *Annals of Behavioral Medicine, 26*, 1-7.

Lucas, G., Gratch, J., King, A., & Morency, L. P. (2014). It's only a computer: virtual humans increase willingness to disclose. *Computers in Human Behaviour, 37*(1), 94-100.

Lutgendorf, S. K., & Ullrich, P. (2002). ognitive processing, disclosure, and health: Psychological and physiological mechanisms. In S. J. Lepore, & J. M. Smyth, *The writing cure: How expressive writing promotes health and emotional wellbeing* (pp. 177-196). Washington, DC, USA: American Psychological Association.

Mabuchi, F., Yoshimura, K., Kashiwagi, K., Yamagata, Z., Kanba, S., Iijima, H., & Tsukaha, S. (2012). Risk factors for anxiety and depression in patients with glaucoma. *Ophthalmology, 96*, 821-825.

Mabuchi, F., Yoshimura, K., Kashiwagik, Shioe, K., Yamagata, Z., Kanba, S., . . . Tsukahara, S. (2008). High Prevalence of Anxiety and Depression in Patients With Primary Open-angle Glaucoma. *Journal of Glaucoma*, 552-557.

Macloed, U., Mitchell, E. D., Burgess, C., Macdonald, S., & Ramirez, A. J. (2009). Risk factors for delayed presentation and referral of symptomatic cancer: evidence for common cancers. *British Journal of Cancer*, 92-101.

Mann, D. M., Ponieman, D., Leventhal, H., & Halm, E. A. (2009). Predictors of adherence to diabetes medications: the role of disease and medication beliefs. *Journal of Behavioural Medicine, 32*(3), 278-284.

Mann, S., Ostroff, J., Winkel, G., Goldstein, L., Fox, K., & Grana, G. (2004). Posttraumatic growth after breast cancer: patient, partner, and couple perspectives. *Psychosomatic Medicine, 66*(3), 442-454.

Marques, A. P., Macedo, A. F., Hernandez-Moreno, L., Ramos, P. L., Butt, T., Rubin, G., . . . Portugese visual impairment study group , (.-g. (2018). The use of informal care by people with vision impairment. *PLoS One, 13*(6), e0198631.

Martin, C. M. (2007). Chronic disease and illness care: Adding principles of family medicine to address ongoing health system redesign. *Canadian Family Physician, 53*(12), 2086–2091.

Masland, R. H. (2012). The Neuronal Organization of the Retina. *Neuron, 76*(2), 266-280.

McCullagh, E., Brigstocke, G., Donaldson, N., & Kalra, L. (2005). Determinants of caregiving burden and quality of life in caregivers of stroke patients. *Stroke, 36*, 2181-2186.

McDonald, L., Turnbull, P., Chang, L., & Crabb, D. P. (2020). Taking the Strain? Impact of glaucoma on patients' informal caregivers. *Eye (Lond.), 34,* 197-204.

McDonald, L., Boodhna, T., Ajtony, C., Turnbull , P., Bourne, R. A., & Crabb, D. P. (2019). Illness perceptions in people newly diagnosed with glaucoma and ocular hypertension. *British Journal of Ophthalmology*.

McDonald, L., Glen, F. C., Taylor, D. J., & Crabb, D. P. (2016). Self-Monitoring Symptoms in Glaucoma: A Feasibility Study of a Web-Based Diary Tool. *Journal of Ophthalmology*, 8.

McDonald, S., Ferguson, E., Hagger, M. S., Foss, A. J., & King, A. J. (2019). A theory-driven qualitative study exploring issues relating to adherence to topical glaucoma medications. *Patient Preference and Adherence, 13*, 819-828.

Medeiros, F. A., & Weinreb, R. N. (2012). Is Corneal Thickness an Independent Risk Factor for Glaucoma? *Ophthalmology, 119*(3).

Medeiros, F. A., Gracitelli, C. P., Boer, E. R., Weinreb, R. N., Zangwill, L. M., & Rosen, P. N. (2015). Longitudinal Changes in Quality of Life and Rates of Progressive Visual Field Loss in Glaucoma Patients. *Ophthalmology*, 293-301.

Medeiros, F., Zangwill, L. M., Bowd, C., Mansouri, K., & Weinreb, R. N. (2012). The Structure and Function Relationship in Glaucoma: Implications for Detection of Progression and Measurement of Rates of Change. *Investigative Ophthalmology and Visual Science, 53*(11), 6939-6946.

Meyer, D., Leventhal, H., & Gutmann, M. (1985). Common-sense models of illness: the example of hypertension. *Health Psychology*, 115-135.

Middelweerd, A., Mollee, J. S., van der Wal, N., Brug, J., & te Velde, S. J. (2014). Apps to promote physical activity in adults: a review and content analysis. *International Journal of Behavioural Nutrition and Physical Activity, 11*(1), 97.

Mills, A. J., Durepos, G., & Wiebe, E. (2010). Reflexivity. In *Encyclopedia of Case Study Research.* Thousand Oaks, CA: SAGE Publications. Retrieved from https://methods.sagepub.com/reference/encyc-of-case-study-research/n290.xml

Mira, J. J., Orozco-Beltran, D., Perez-Jover, V., Martinez-Jimeno, L., Gil-Guillen, V. F., & Carratala-Munuera, C. (2013). Physician patient communication failure facilitates medication errors in older polymedicated patients with multiple comorbidities. *Family Practice, 30*(1), 56-63. doi:https://doi.org/10.1093/fampra/cms046

Mirzaei, M., Aspin, C., Essue, B., Jeon, Y., Dugdale, P., Usherwood, T., & Leeder, S. (2013). A patient-centred approach to health service delivery: improving health outcomes for people with chronic illness. *BMC Health Services Research, 13*(1), 251.

Mitchell, J., & Bradley, C. (2006). Quality of life in age-related macular degeneration: a review of the literature. *Health and Quality of Life Outcomes*, 97.

Mok, E., Chan, F., Chan, V., & Yeung, E. (2013). Perception of empowerment by family caregivers of patients with a terminal illness in Hong Kong. *International Journal of Palliative Nursing, 8*(3), 137-145.

Mor, N., & Winquist, J. (2002). Self-focused attention and negative affect: a meta-analysis,. *Psychological Bulletin, 128*(4), 638-662.

Moss-Morris, R., Weinman, J., Petrie, K., Horne, R., Cameron, L., & Buick, D. (2002). The Revised Illness Perception Questionnaire (IPQ-R). *Psychology and Health, 17*(1), 1-16.

Mudie, L. I., LaBarre, S., Varadaraj, V., Karakus, S., Onnela, J., Munoz, B., & Friedman, D. S. (2016). The Icare HOME (TA022) Study: Performance of an Intraocular Pressure Measuring Device for Self-Tonometry by Glaucoma Patients. *Ophthalmology, 123*(8), 1675-1684.

National Institute for Health and Care Excellence. (2017). *Glaucoma: diagnosis and management.*

Nelson, P., Aspinall, P., Papasouliotis, O., Worton, B., & O'Brien, C. (2003). Quality of Life in glaucoma and its relationship with visual function. *Journal of Glaucoma*, 139-150.

Newman-Casey, P. A., Robin, A. L., Blachley, T., Farris, K., Heisler, M., Resnicow, K., & Lee, P. P. (2015). Most Common Barriers to Glaucoma Medication Adherence: A Cross-Sectional Survey. *Ophthalmology, 122*(7), 1308-1316.

Newman-Casey, P. A., Weizer, J. S., Heisler, M., Lee, P. P., & Stein, J. D. (2013). Systematic Review of Educational Interventions to Improve Glaucoma Medication Adherence. *Seminars in Opthalmology*, 191-201.

Nordmann, J., Auzanneau, N., Ricard, S., & Berdeaux, G. (2003). Vision related quality of life and topical glaucoma treatment side effects. *Health and Quality of Life Outcomes*, 75.

Northouse, L. L., Katapodi, M. C., Schafenecker, A. M., & Weiss, D. (2012). The Impact of Caregiving on the Psychological Wellbeing of Family Caregivers and Cancer Patients. *Seminars in Oncology Nursing, 28*(4), 236-245.

Nyman, S. R., Dibb, B., Victor, C. R., & Gosney, M. A. (2012). Emotional wellbeing and adjustment to vision loss in later life: a meta-synthesis of qualitative studies. *Disability and Rehabilition, 34*(12), 971-981.

Odberg, T., Jakobsen, J. E., Hultgren, S. J., & Halseide, R. (2001). The impact of glaucoma on the quality of life of patients in Norway. I. Results from a self-administered questionnaire. *Acta Ophthalmologica Scandinavica, 79*(2), 116-120.

Olthoff, C. M., Schouten, J. S., van de Borne, B. W., & Webers, C. A. (2005). Noncompliance with ocular hypotensive treatment in patients with glaucoma or ocular hypertension an evidence-based review. *Ophthalmology, 112*(6), 953-961.

Parrish, R. K., Gedde, S. J., Scott, I. U., Feuer, W. J., Schiffmann, J. C., Mangione, C. M., & Montenegro-Pinniella. (1997). Visual function and quality of life among patients with glaucoma. *Archives of Ophthalmology*, 115.

Pesut, D. P., Bursuc, B. N., & Bulajic, M. V. (2014). Illness perceptions in tuberculosis by implementation of the Brief Illness Perception Questionnaire – A TBNET Study. *SpringerPlus, 3*, 664.

Peters , D., Heijl, A., Brenner, L., & Bengtsson, B. (2015). Visual impairment and vision related quality of life in the early manigest glaucoma trial after 20 years of follow up. *Acta Ophthalmologica, 93*(8), 745-752.

Peters, M., Jenkinson, C., Doll, H., Playford, D., & Fitzpatrick, R. (2013). Carer quality of life and experiences of health services: a cross-sectional survey across three neurological conditions . *Health and Quality of Life Outcomes, 11*, 103.

Peterson-Sweeney, K., McMullen, A., Lorrie Yoos, H., Kitzmann, H., Halterman, J. S., Sidora Arcoleo, K., & Anson, E. (2007). Impact of asthma education received from health

care providers on parental illness representation in childhood asthma. *Research in Nursing and Health, 30*(2), 203-212.

Petrie, K. J., & Weinman, J. (2006). Why illness perceptions matter. *Clinical Medicine*, 536-539.

Petrie, K., Jago, L. A., & Devcich, D. A. (2007). The role of illness perceptions in patients with medical conditions. *Current opinion in psychiatry, 20*, 163-167.

Pierce, J. L., Kostova, T., & Dirks, K. (2003). The state of psychological ownership: Integrating and extending a century of research. *Review of General Psychology, 7*(1), 84-107.

Piette, J. D., Farris, K. B., Newman, S., An, L., Sussman, J., & Singh, S. (2015). The potential impact of intelligent systems for mobile health self-management support: Monte Carlo simulations of text message support for medication adherence. *Annals of Behavioral Medicine, 49*(1), 84-94.

Pozarowska, D., & Pozarowski, P. (2016). The era of anti-vascular endothelial growth factor (VEGF) drugs in ophthalmology, VEGF and anti-VEGF therapy. *Central European Journal of Immunology, 41*(3), 311-316.

Quigley , H. A., Dunkelberger, G. R., & Green, W. R. (1989). Retinal Ganglion Cell Atrophy Correlated With Automated Perimetry in Human Eyes With Glaucoma. *American Journal of Ophthalmology, 107*(5), 453-464.

Quigley, H. A. (1996). Number of people with glaucoma worldwide. *British Journal of Ophthalmology, 80*, 389-393.

Quigley, H. A., & Broman, A. T. (2006). The number of people with glaucoma worldwide in 2010 and 2020. *British Journal of Ophthalmology, 90*(3), 262-267.

Rainie, L., & Fox, S. (2000). *The Online Health Care Revolution.* Washington, DC, USA: Pew Research Center.

Ramirez, A. J., Westcombe, A. M., Burgess, C. C., Sutton, S., Littlejohns, P., & Richards, M. A. (1999). Factors predicting delayed presentation of symptomatic breast cancer: a systematic review. *Lancet, 353*(9159), 1127-1131.

Ramulu, P. (2009). Glaucoma and Disability: Which tasks are affected, and at what stage of disease? *Current Opinion in Ophthalmology*, 92-98.

Ramulu, P. Y., Hochberg, C., Maul, E. A., Chan, E. S., Ferrucci, L., & Friedman, D. S. (2014). Glaucomatous visual field loss associated with less travel from home. *Optometry and Vision Science*, 187-193.

Ramulu, P. Y., Maul, E., Hochberg, C., Chan, E. S., Ferrucci, L., & Friedman, D. S. (2012). Real-World Assessment of Physical Activity in Glaucoma Using an Accelerometer. *Ophthalmology*, 1159-1166.

Read, S., Waterman, H., Morgan, J. E., Harper, R. A., Spencer, A. F., & Stanford, P. (2018). Glaucoma, dementia, and the "precipice of care": transitions between states of medication adherence. *Patient Prefer Adherence, 12*, 1315-1325.

Reblin, M., & Uchino, B. N. (2008). Social and emotional support and its implications for health. *Current Opinion in Psychiatry*, 201-205.

Rees, G., Chong, X., Cheung, X. Y., Aung, T., Friedman, D. S., Crowston, J. G., & Lamoureux, E. L. (2014). Beliefs and Adherence to Glaucoma Treatment: A Comparison of Patients From Diverse Cultures. *Journal of Glaucoma*, 293-298.

Rees, G., Leong, O., Crowston, J. G., & Lamoureux, E. L. (2010). Intentional and unintentional nonadherence to ocular hypotensive treatment in patients with glaucoma. *Ophthalmology, 117*, 903-908.

Richardson, A. E., Morton, R., & Broadbent, E. (2015). Caregivers' Illness Perceptions Contribute to Quality of Life in Head and Neck Cancer Patients at Diagnosis. *Journal of Psychosocial Oncology, 33*(4), 414-432.

Richardson, C., Brunton, L., Olleveant, N., Henson, D. B., Pilling, M., Mottershead, J., . . . Waterman, H. (2013). A study to assess the feasibility of undertaking a randomized controlled trial of adherence with eye drops in glaucoma patients. *Patient Preference and Adherence, 7*, 1025-1039.

Richman, J., Lorenzana, L. L., & Lankaranian, D. (2010). Importance of Visual Acuity and Contrast Sensitivity in Patients With Glaucoma. *Archives of Ophthalmology*, 1576-1582.

Ross, S., Walker, J., & MacLoed, M. J. (2004). Patient compliance in hypertension: The role of illness perceptions and treatment beliefs. *Journal of Human Hypertension, 18*, 607-613.

Royal College of General Practitioners. (2012). *Matters of life and death: helping people to live well until they die*. (Royal College of General Practitioners and Royal College of Nursing) Retrieved December 2016, from http://www.rcgp.org.uk/clinical-and-research/toolkits/~/media/Files/CIRC/Matters%20of%20Life%20and%20Death%20FINAL.ashx

Safran, A. B., & Landis, T. (1999). From cortical plasticity to unawareness of visual field defects. *Journal of Neuro-Ophthalmology, 19*(2), 84=88.

Salmon, N. J., Terry, H. P., Farmery, A. D., & Salmon, J. F. (2007). An analysis of patients discharged from a hospital-based glaucoma case-finding clinic over a 3-year period. *Ophthalmic and Physiological Optics, 27*(4), 399-403.

Sambhara, D., & Aref, A. A. (2014). Glaucoma management: relative value and place in therapy of available drug treatments. *Therapeutic Advancements in Chronic Disease, 5*(1), 30-43.

Sarkar, U., Fisher, L., & Schillinger, D. (2006). Is self-efficacy associated with diabetes self-management across race/ethnicity and health literacy? *Diabetes Care*, 823-829.

Saunders, L. J., Medeiros, F. A., Weinreb, R. N., & Zangwill, L. M. (2016). What rates of glaucoma progression are clinically significant? *Expert Review of Ophthalmology*, 227-234.

Saunders, L. J., Russell, R. A., & Crabb, D. P. (2012). Practical landmarks for visual field disability in glaucoma. *British Journal of Ophthalmology, 96*(9), 1185-1189.

Saunders, L. J., Russell, R. A., & Kirwan, J. F. (2014). Examining visual fields loss in patients in glaucoma clinics during their predicted remaining lifetime. *Investigative Ophthalmology and Visual Science, 55*, 102-109.

Saw, S. M., Gazzard, G., & Friedman , D. S. (2003). Awareness of glaucoma, and health-related beliefs of patients suffering primary acute angle closure. *British Journal of Ophthalmology, 87*, 446-449.

Sawyer, A. T., Harris, S. L., & Koening, H. G. (2019). Illness perception and high readmission health outcomes. *Health Psychology Open, 6*(1). doi:https://dx.doi.org/10.1177%2F2055102919844504

Sayera, S. L., Riegel, B., Pawlowski, S., Coyne, J. C., & Samaha, F. F. (2008). Social support and self-care of patients with heart failure. *Annals of Behavioral Medicine, 35*(1), 70-79.

Scharloo, M., Kaptein, A. A., Weinman, J. A., Hazes, J. M., Breedveld, F. C., & Rooijmams, H. G. (1999). Predicting functional status in patients with rheumatoid arthritis. *Journal of Rheumatology*, 1686-1693.

Scharloo, M., Kaptein, A. A., Weinman, J., Hazes, J. M., Willems, L. N., Bergman, W., & Roojimans, H. G. (1998). Illness perceptions, coping and functioning in patients with rheumatoid arthritis, chronic obstructive pulmonary disease and psoriasis. *Journal of Psychosomatic Research, 44*(5), 573-585.

Schmier, J. K., Halpern, M. T., Covert, D., Delgado, J., & Sharma, S. (2006). Impact of visual impairment on use of caregiving by individuals with Age-Related Macular Degeneraton. *Retina, 26*(9), 1056-1062.

Schrag, A., Selai, C., Jahanshahi, M., & Quinn, N. P. (2000). The EQ-5D—a generic quality of life measure—is a useful instrument to measure quality of life in patients with Parkinson's disease. *Journal of Neurology, Neurosurgery and Psychiatry, 69*(1), 67-73.

Schwartz, G. F., & Quigley, H. A. (2008). Adherence and persistence with glaucoma therapy. *Survey of Ophthalmology, 53*, 57-68.

Seamark, D. A., Blake, S. D., & Seamark, C. J. (2004). Living with severe chronic obstructive pulmonary disease (COPD): perceptions of patients and their carers. An interpretative phenomenological analysis. *Palliative Medicine, 18*(7).

Shtein, R. M., Newman-Casey, P. A., Herndon, L., Coleman, A. L., & Lee, P. P. (2016). Assessing the Role of the Family/Support System Perspective in Patients With Glaucoma. *Journal of Glaucoma*, e676-e680.

Skalicky, S. E., Lamoureux, E. L., Crabb, D. P., & Ramulu, P. Y. (2019). Patient-reported Outcomes, Functional Assessment, and Utility Values in Glaucoma. *Journal of Glaucoma, 28*(2), 89-96.

Slabaugh, M., & Salim, S. (2017). Use of Anti-VEGF Agents in Glaucoma Surgery. *Journal of Ophthalmology*, 6.

Smith, J. A., & Osborn, M. (2012). Interpretative Phenomenological Analysis. In J. A. Smith, *Qualitative Psychology* (pp. 53-80). California, USA: SAGE.

Smith, J. A., & Osborn, M. (2015). Interpretative phenomenological analysis as a useful methodology for research on the lived experience of pain. *British Journal of Pain, 9*(1), 41-42.

Smith, N. D., Crabb, D. P., & Garway-Heath, D. F. (2011). An exploratory study of visual search performance in glaucoma. *Ophthalmic and Physiological Optics*, 225-232.

Stablein, T., Hall, J., Pervis, C., & Anthony, D. (2015). Negotiating stigma in health care: disclosure and the role of electronic health records. *Health Sociology Review, 24*(3), 227-241.

Stamper, R. L., Wigginton, S. A., & Higginbotham, E. J. (2002). Primary Drug Treatment for Glaucoma: Beta-Blockers Versus Other Medications. *Survey of Ophthalmology, 47*(1), 63-67.

Stanford, P., Waterman, H., Russell, W. B., & Harper, R. A. (2009) Psychosocial adjustment in age related macular degeneration. *The British Journal of Visual Impairment, 27*(2), 129-146,

Taylor, S. E., & Aspinwall, L. G. (1996). Psychosocial aspects of chronic illness. In P. T. Costa, & G. R. VandenBos, *Psychological aspects of serious illness: chronic conditions, fatal diseases, and clinical care* (pp. 7-60). Washington. DC, USA: American Psychological Association.

Tejeria, L., Harper, R. A., Artes, P. H., & Dickinson, C. M. (2002). Face recognition in age related macular degeneration: perceived disability, measured disability, and performance with a bioptic device. *British Journal of Ophthalmology*, 1019-1026.

Thompson, R. J., Mata, J., Jaeggi, S. M., Buschkuehl, M., Jonides, J., & Gotlib, I. H. (2010). Maladaptive Coping, Adaptive Coping, and Depressive Symptoms: Variations across Age and Depressive State. *Behavioural Research and Therapy, 48*(6), 459-466.

Thornton, M., & Travis, S. S. (2003). Analysis of the reliability of the modified caregiver strain index. *J Gerontol B Psychol Sci Soc Sci., 58*(2), S127-S13.

Timmins, N. (2008). NHS goes to the PROMS. *British Medical Journal, 336*, 1464-1465.

Tsai, J. (2005, June 15). *How to Evaluate the Suspicious Optic Disc*. (Review of Ophthalmology) Retrieved April 17, 2018, from https://www.reviewofophthalmology.com/article/how-to-evaluate-the-suspicious-optic-disc

Tsai, J. C., McClure, C. A., Ramos, S. E., & Schlundt, D. G. (2003). Compliance barriers in glaucoma: a systematic classification. *Journal of Glaucoma, 12*, 393-398.

Turano, K. A., Rubin, G. S., & Quigley, H. A. (1999). Mobility performance in glaucoma. *Investigative Ophthalmology and Visual Science*, 2803-2809.

Turner, J., & Kelly, B. (2000). Emotional dimensions of chronic disease. *Western Journal of Medicine, 172*(2), 124-128.

Turnquist, D. C., Harvey, J. H., & Andersen, B. L. (1988). Attributions and adjustment to life-threatening illness. *British Journal of Clinical Psychology, 27*, 55-65.

Van den Burg, B., Al, M., Van Exel, J., Koopmanschap, M., & Brouwer, W. (2008). Economic valuation of informal care: conjoint analysis applied in a heterogeneous population of informal caregivers. *Value in Health, 11*(7), 1041-1050.

Van den Heuvel, E., de Witte, L., Schure, L., Sanderman, R., & Meyboom-de Jong, B. (2001). Risk-factors for burn-out in caregivers for stroke patients, and possibilities for intevention. *Clinical Rehabilition, 40*(2), 669-667.

van der Hiele, K., van Gorp, D. A., Heerings, M. A., Jongen, P., van der Klink, J. J., Frequin, S. T., . . . Visser, L. H. (2019). Caregiver strain among life partners of persons with mild disability due to relapsing-remitting multiple sclerosis. *Multiple Sclerosis and Related Disorders, 31*, 5-11.

van Hout, B., & Janssen, M. F. (2012). Interim scoring for the EQ-5D-5L: Mapping the EQ-5D-5L to EQ-5D-3L value sets. . *Value in Health, 15*(5), 708-715.

Van Nispen, R. M., de Boer, M. R., & Hoeijmakers, J. G. (2009). Co-morbidity and visual acuity are risk factors for health-related quality of life decline: five-month follow-up EQ-5D of visually impaired older patients. *Health and Quality of Life Outcomes, 7*, 7-18.

Vickerstaff, V., Ambler, G., Bunce, C., Xing, W., & Gazzard, G. (2015). Statistical analysis plan for the Laser-1st versus Drops-1st for Glaucoma and Ocular Hypertension Trial (LiGHT): a multi-centre randomised controlled trial. . *Trials*, 16.

Vogeli, C., Shields, A. E., Lee, T. A., Gibson, T. B., Marder, W. D., Weiss, K. B., & Blumenthal, D. (2007). Multiple Chronic Conditions: Prevalence, Health Consequences, and Implications for Quality, Care Management, and Costs. *Journal of General Internal Medicine, 22*(3), 391-395.

von Korff, M., Gruman, J., Schaefer, J., Curry, S. J., & Wagner, E. H. (1997). Collaborative management of chronic illness. *Annals of Internal Medicine, 127*(12), 1097-1102.

Vukicevic, M., Heraghty, J., Cummins, R., Gopinath, B., & Mitchell, P. (2016). Caregiver perceptions about the impact of caring for patients with wet age-related macular degeneration. *Eye (Lond), 30*(3), 413-421.

Waisbourd, M., Dhami, H., Zhou, C., Hsieh, M., Abichandani, P., Pro, M. J., . . . Myers, J. S. (2016). The Wills Eye Glaucoma App: Interest of Patients and Their Caregivers in a Smartphone-based and Tablet-based Glaucoma Application. *Journal of Glaucoma*, 787-791.

Waterman, H., Brunton, L., Fenerty, C., Mottershead, J., Richardson, C., & Spencer, F. (2013). Adherence to ocular hypotensive therapy: patient health education needs and views on group education. *Patient Preference and Adherence, 7*, 55-63.

Weinreb, R. B., & Khaw, P. T. (2004). Primary open-angle glaucoma. *The Lancet*, 1711-1720.

Weiss, D., & Lang, F. R. (2012). “They” are old but “I” feel younger: Age-group dissociation as a self-protective strategy in old age. *Psychology and Aging, 27*(1), 153-163.

White, M. H., & Dorman, S. M. (2000). Online support for caregivers. Analysis of an Internet Alzheimer mailgroup. *Computers in Nursing, 18*(4), 168-176.

White, M. H., & Dorman, S. M. (2001). Receiving social support online: implications for health education. *Health Education Research, 16*(6), 693-707.

Wiebe, D., & Korbel, C. (2003). Defensive denial, affect, and the self-regulation of health threats. In L. D. Cameron, & H. Leventhal, *The self-regulation of health and illness behaviour* (pp. 184-203). New York, USA: Routledge.

Wilensky, J. T., & Chen, T. C. (1996). Long-term results of trabeculectomy in eyes that were initially successful. *Transactions of the American Ophthalmological Society, 94*, 147-164.

Williams, L., O'Connor, R. C., Grubb, N. R., & O'Carroll, R. E. (2011). Type D personality and illness perceptions in myocardial infarction patients. *Journal of Psychosomatic Research, 70*(2), 141-144.

Wolfram, C., Stahlberg, E., & Pfeiffer, N. (2019). Patient-Reported Nonadherence with Glaucoma Therapy. *Journal of Ocular Pharmacology and Therapeutics, 35*(4), 223-228.

Wood, A. M., Froh, J. J., & Geraghty, A. W. (2010). Gratitude and wellbeing: A review and theoretical integration. *Clinical Psychology Review*, 16.

Wood, J. M., Black, A. A., Mallon, K., Thomas, R., & Owsley, C. (2016). Glaucoma and driving: on-road driving characteristics. *PLOS One*, 1371.

Wright, H. R., & Diamond, J. P. (2014). ervice innovation in glaucoma management: using a web-based electronic patient record to facilitate virtual specialist supervision of a shared care glaucoma programme,. *British Journal of Ophthalmology, 99*(3), 313-317.

Wu, P., Xi, S., Xia, H., Lu, H., & Guo, W. (2014). Survey on Vision-related Quality of Life and Self-management Among Patients With Glaucoma. *Journal of Glaucoma, 23*(2), 75-80.

Yaqub, M. (2012). Visual fields interpretation in glaucoma: a focus on static automated perimetry. *Community Eye Health, 25*(79-80), 1-8.

Yee, J., & Schulz, R. (2000). Gender differences in psychiatric morbidity among family caregivers: a review and analysis. *The Gerontologist, 36*, 147-164.

York Cornwell, E., & Waite, L. J. (2009). Social Disconnectedness, Perceived Isolation, and Health among Older Adults. *Journal of Health and Social Behaviour, 50*(1), 31-48. doi:https://doi.org/10.1177%2F002214650905000103

Zelber-Sagi, S., Bord, S., Dror-Lavi, G., Smith, M. L., Towne, S. D., Buch, A., . . . Shibolet, O. (2017). Role of illness perception and self-efficacy in lifestyle modification among

non-alcoholic fatty liver disease patients. *World Journal of Gastroenterology, 23*(10), 1881-1890.

Appendices

Appendix 1 – Research protocol (Chapter Four and Five)

Taking the strain? Impact of glaucoma on patient's informal caregivers

Date and version number: Version 2.0. 08/05/2017.

Study Team

Principal Investigator	Professor David Crabb (City, University of London)
Co-Investigator	Ms Lydia Chang (Hinchingbrooke Hospital NHS Trust)
Researcher/Lead author	Ms Leanne McDonald (City, University of London)
Research co-ordinators	Ms Paula Turnbull (Hinchingbrooke Hospital NHS Trust)

Ms Manjo Doug (Hinchingbrooke Hospital NHS Trust)

Abstract

Glaucoma is a chronic condition characterised by progressive optic nerve head damage, potentially resulting in irreversible visual impairment in some patients. It does not get better on its own and cannot be cured completely. Fortunately, only a minority of treated patients become significantly visually impaired in their lifetime. Nevertheless, studies have demonstrated patient's quality of life to be affected before significant sight loss occurs; these studies focus exclusively on changes in patients. Little attention has been given to the impact of glaucoma on the lives of patient's partners or informal caregivers. Research has been undertaken in *caregiver-strain* in life threatening conditions like cancer and more recently, in chronic conditions such as multiple sclerosis, Parkinson's and Alzheimer's disease. This has led to established methodology for assessing well-being in informal caregivers for these conditions. We plan to use this methodology to estimate, for the first time, the position of glaucoma on the spectrum of conditions that impact on the well-being of partners and informal-carers. This will be done using a cross-sectional postal survey of 300 patients with moderate to advanced stage glaucoma using a standardised 13 item questionnaire. We anticipate glaucoma may have an effect not captured by the established methodology. So we therefore also aim to conduct interviews (focus groups – qualitative work) to tease out these themes; for example, the responsibilities of a partner supporting adherence to treatment, the burden on the carer when the patient experiences giving up activities, loss of driving licence, loss of self-confidence and fear of blindness. The outcomes of this research, conducted over a 15 month period, will be disseminated via an article in an open-

access journal and will be presented at academic meeting such as the UK and Eire Glaucoma Society meeting in December 2017 and the Association for Research in Vision and Ophthalmology (ARVO) meeting in May 2018

List of abbreviations

COREQ	Consolidated Criteria for Reporting Qualitative Research
CP	Caregiver Participant
EPR	Electronic Patient Record
EQ-5D	EuroQol Group's 5 dimension health status questionnaire
FG	Focus Group
MCSI	Modified Carer Strain Index
MD	Mean Deviation
NICE	National Institute for Health and Clinical Excellence
PD	Parkinson's Disease
PP	Patient Participant
SD	Standard Deviation
UK	United Kingdom

Background

Physical, psychological and emotional change due to caring for someone with an illness can be termed *caregiver strain* [1]. An *informal caregiver* can be defined as someone (spouse, partner, close friend or family member) who helps to care for a person with an illness but not in a formal capacity. Informal caregivers demonstrating significant caregiver strain can, for example, experience exhaustion, problems with wellbeing and reduced level of self-esteem [2].

Caregiver strain is most likely to affect women and those who do not have adequate social support themselves [3-5]. Conversely, informal caregivers who are psychologically well adjusted, have good social support and implement proactive coping strategies are less likely to suffer from caregiver strain [1]. Informal caregivers often do not report their caregiver status to healthcare professionals and as such may not receive appropriate support [6]. Research into informal caregiver burden in eye disease may provide a platform for improving voluntary care and ultimately patient outcomes.

Caregiver strain is well studied in conditions, like cancer, where the burden of care is clearly significant. More recently, caregiver stain in 'silent' long-term conditions has received attention; many of these chronic conditions are age-related and are becoming more prevalent because of changing demographics. Caregiver strain has recently been investigated in age related macular degeneration [7, 8]. There has been no significant investigation into caregiver strain in glaucoma and this is the main idea of this proposed programme of work. Comparing the caregiver strain associated with glaucoma against a spectrum of other common age-related chronic conditions would be useful new knowledge.

We have recently published results from a qualitative study of functional implications and coping behaviours in people living with glaucoma. The patient interviews were revealing on many levels. Interestingly some patients reported reliance on practical support from family members/friends and others described a fear of becoming a burden to their informal caregiver [9]. We think a similar study in informal caregivers of people with glaucoma might reveal subtle burdens that are unique to glaucoma.

Aims

To estimate informal caregiver strain in people with glaucoma using a standardised instrument and compare estimates to other chronic conditions.

To assess factors affecting development of caregiver strain in a sample of informal caregivers to those with glaucoma.

Plan of Investigation - Overview

Both quantitative and qualitative methodology (mixed methods) will be used in order to investigate the study aims.

The quantitative element of the research (part 1) will be a cross-sectional study focussing on estimating the level of standardised caregiver strain using the modified carer strain index (MCSI) [12]; this instrument tests whether aspects of the caregivers' lives, such as sleep, finances and normal routine have been affected by their caring role, and whether this has placed a physical and mental strain upon them. The MCSI is short (13 items) and has been widely validated (cited 122 times) [12]. The MCSI has been applied to a variety of chronic diseases [1, 13, 14]; it has the advantage of not being disease-specific, and is therefore easily applied to other populations. MCSI is scored to create an aggregate (0-26) with a higher score indicating higher burden. MCSI will therefore be the main outcome measure for this study and will allow us to place glaucoma on the spectrum of chronic diseases that carry significant carer burden. In this study we plan to consider that population of patients with visual field damage in both eyes; we will specifically test the hypothesis that these patients will have a different average MCSI compared to neurological conditions, for example, Parkinson's disease.

The qualitative element of the research (Part 2) will also be a cross-sectional study to investigate the specific roles that informal caregivers have in glaucoma care. We anticipate MCSI will not necessarily capture glaucoma specific problems faced by informal care givers in glaucoma. We speculate these unique informal caregiver strains might include, for example, care-giver help with adherence to treatment; giving up joint activities; dependence to help with everyday tasks; threat of losing a driving licence, worries about falls/mobility and the psychological burden fear of sight loss. We will test the idea that these subtle factors might accumulate into caregiver strain specific to those with glaucoma.

Quantitative study (Study 1) - Details

A cross-sectional postal survey will be used for this study. Participants are defined as a Patient Participant (PP) or Caregiver Participant (CP). All participants must be over the age of 18 years old, but there is no upper age limit on participation. PPs will be identified using the electronic patient record (EPR) from glaucoma clinics. Inclusion criteria, ascertained from the EPR, for PPs will be:

A clinical diagnosis of primary open angle glaucoma

No other significant ocular comorbidity. (PPs will not be excluded if they have had cataract extraction and intraocular lens implantation.)

Advanced visual field loss in both eyes (Using most recent Humphrey Visual Field with mean deviation (MD) worse than -12dB in the better eye, where the better eye

is defined as having the better MD) or a trabeculectomy procedure since January 2015.

PPs will then be contacted by post to be invited into the study. The posted invitation pack will include a patient information document and questionnaire. PP's will be asked to identify a CP, if they have one.

We will post questionnaire materials to 300 potential participants. We expect a response rate of around 30%, similar to Peters et al. [1] aiming to recruit 75 pairs of participants (150 participants in total). A thank you/reminder letter will be sent two weeks after the initial survey materials in order to attempt to maximise response rate. We will record invited PPs' date of diagnosis, current best corrected visual acuity, most recent visual field results, age and co-morbidities (visual and otherwise) from the EPR.

The study invitation letter will ask PP's to identify somebody that they feel provides support with their glaucoma;

"Can you identify someone who is an informal caregiver for your glaucoma? This might be a spouse, a partner, a relative or friend who helps you with any aspect related to your glaucoma." Yes/No

If PPs do not have an informal caregiver, they will be asked to select 'No', we will ask if they can record their demographic details (sex, age, ethnicity and education level) and complete the EQ-5D and to post back to the researcher.

Inclusion criteria for CP are as follows;

The informal caregiver cannot be a professional or belong to a formal patient support network. If the PP selects 'yes', the CP will be asked to agree with the following question to check their eligibility;

"Are you a person who voluntarily helps a patient with aspects related to their glaucoma (e.g. attending appointments, providing assistance with eye drops)?'

CPs will be invited to self-identify any diagnosis of a cognitive impairment, example, dementia;

'Have you ever been diagnosed with a physical or mental illness (for example, dementia) that may affect your ability to fill in the questionnaires?'

Participants with a self-reported diagnosis of cognitive impairment will be excluded. CPs will be asked to record the type of relationship between themselves and the patient (e.g. spouse, relative [type], friend or other). CPs will be asked to record their sex, age, ethnicity and education level.

CPs and PPs will be asked to read a participant information document, sign the attached consent form and then invited into the study. Due to the postal nature of the survey, participants will be asked to agree to the following statement;

'I understand that, by returning the questionnaire materials, I agree to take part in the research study described in this information sheet'.

This therefore represents "implied consent". We will state in the guidance letter that if they send the questionnaire back, we will assume both CP and PP have consented. In order to ensure that responses remain private, we will send two stamped, addressed envelopes, marked yellow and green to correspond with the different coloured paper on the questionnaire packs.

Both CPs and PPs will be asked to complete the EQ-5D [15], which is a five item measure used to assess general health.

Main outcome measure: Modified Caregiver Strain Index (MCSI) score.

Proposed sample size

Results will be compared to those reported in the Peters et al study (2013) [1]. Here, for example, mean (95% confidence interval) MCSI was 11.9 (11.4-12.4) in their sample of n=571 participants for Parkinson's disease (PD).

From these figures the SD of the MCSI score is derived to be approximately ~6.

That is (0.5/2)*sqrt [571]. Therefore a sample-size calculation for a *one-sample t-test* aiming to demonstrate a mean difference of 2 (~ 7.5% difference on the 0-26 scale) between an average MCSI score for glaucoma compared to an average MCSI score for PD as described in Peters et al (2013) (power [beta] and alpha set at 0.80 and 0.05 respectively) yields a sample size of at least 73 participants required (Minitab 17 Statistical Software (2010). (www.minitab.com)).

A planned sample of 75 pairs of participants for part 1 of the study is sufficient in order to test the main hypothesis that mean MCSI scores from glaucoma are different to those from other neurological conditions.

Data management and planned statistical analysis

The questionnaire data will be computerised and stored in the secure data store in the Crabb Lab at City, University of London. Only researchers associated with the project will have access to the data. All quantitative data will be analysed by Leanne McDonald, PhD student, under the supervision of Professor David Crabb using SPSS V.23. We will calculate average MCSI and compare to previously reported values for other chronic conditions (one sample t-test). We will also conduct a series of secondary analyses, such as associations between the outcome of interest (MCSI) and age, severity of vision loss and other factors using multiple regression analysis. We will compare demographic and EQ-5D data for patients with a caregiver and patients without a caregiver. Qualitative data (from the focus groups) will be analysed using thematic analysis.

Qualitative Study (Part 2) – Details

Participants indicating interest in taking part in future research in Part 1 will be invited by postal invitation to take part in a focus group. Two focus groups (FGs) will be conducted. The FGs will be run on a separate day and participant travel expenses will be made available. We expect each FG to last one and a half hours.

Recommended number of individuals per FG is 6-8 [16] and so each FG will each consist of 4 pairs of PPs and CPs.

FGs are less formal than interviews and are led primarily by the participants involved, with the researcher acting as a facilitator. The FGs in this study will be run by Ms Leanne McDonald, a PhD researcher at City University London, who has training and experience in facilitating FGs. FGs enable participants to share ideas and experiences with each other, creating a more impulsive dialogue. Group interaction encourages participants to explore shared perspectives and supports the participation of people who may be reluctant to contribute their views [17]. Significantly our research team has published expertise using FGs [18]. A pilot topic guide will be devised in conjunction with two patients (Ms Carol Bronze and Ms Julia Brazier) who have been strategically involved in our research lab's PPI activities previously. All dialogue from the FGs will be audio-recorded (with

permission from the participants) transcribed and reviewed by the investigators in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) for FGs [19] . Framework analysis, using the qualitative software package NVIVO 10.2 (QSR International, Cambridge, Massachusetts) will be used to organise, refine and condense themes for exploration [20]. Themes and sub-themes will be reported and summarised using a coding tree.

Outcomes and dissemination

We plan to report results from our study in an article submitted to an open-access journal. We also plan to disseminate results at the UK and Eire Glaucoma Society Meeting in 2017 and at the Association for Research in Vision and Ophthalmology in 2018. We will also ask the International Glaucoma Association if we can disseminate findings in their patient publications.

Currently there is an unmet need, highlighted by the NICE guidelines [11], for information for 'families and carers' of people newly diagnosed with glaucoma. At a later stage, the research team may use the results of the study (part 2 FG work) to provide some evidence based information for this unmet need. The results from this research may give us the opportunity to take advantage of our expertise and experience in developing award winning patient information. (http://www.city.ac.uk/news/2015/september/new-app-demystifies-glaucoma). After the project we will interact with the IGA in order to see how these can be publicised and made available.

The National Institute for Health and Care Excellence (NICE, 2009) guidelines for glaucoma care recommend support groups for patients [11]. The NICE guidelines also state that 'families and carers should also be given the information and support that they need', however there is currently no formal support available for caregivers. This research may provide groundwork for creating a support groups for informal caregivers. If health services (ophthalmologists, nurses, community optometrists) and social care services (social workers, charity groups) were able to routinely identify caregivers who may be having problems, it may be possible to improve services. For example, carer support groups, and lead to better understanding and positive outcomes. This work might lead to an application (by us or others) to the National Institute for Health Research to study the health service delivery implications of our findings. With permission, the results of this study may, in future work, be translated into materials aimed at supporting patients and caregivers with their glaucoma journey.

Ethical considerations

The research being proposed will be of a sensitive nature due to the subject material being discussed, however, there is a low risk of participant harm.

Participants will be asked not to take part in the study if they feel that the subject matter may be distressing to them. Participants will be told their data will be anonymised and will only be accessed by the researchers affiliated with this project – who the participants will have contact details for.

It is important that the distinction between an 'informal caregiver' and 'formal carer' is made to participants. Some participants may not feel that the help they provide should be classified as 'care' and definitions of the word 'carer' differ among individuals. This will also help to minimise any distress that patients may experience by having their care needs identified.

During the focus group sessions, the researchers will record participants' voices so that they may be transcribed later. Participants taking part in the focus group will be required to sign a separate consent form giving permission to have their voices recorded and listened to later by the researchers. Both the qualitative and quantitative data will be stored on a secure computer at City University London, which only the researchers will have access to. The data will be destroyed after the University statutory period, which is 10 years.

Patient benefit

To our knowledge this research will be the first of its kind to be conducted with glaucoma patients and their caregivers. By identifying risk factors (predictors) for informal caregiver strain in glaucoma caregivers, it may be possible to develop resources and support systems in the future to monitor patients and caregivers. Educating patients and caregivers in this way and providing support is particularly relevant as the prevalence of glaucoma is expected to rise significantly due to the ageing population, so the number of patients and informal caregivers will rise. Similar research in other caregiver groups has generated interest from the medical and psychological communities.

References

1. Peters, M., Jenkinson, C., Doll, H., Playford, D. & Fitzpatrick, R. (2013) Carer quality of life and experiences of health services: a cross-sectional survey across three neurological conditions *Health and Quality of Life Outcomes* 11:103.
2. Van den Heuvel, E., de Witte, L., Schure, L., Sanderman, R. & Meyboom-de Jong, B. (2001) Risk-factors for burn-out in caregivers for stroke patients, and possibilities for intervention. *Clinical Rehabilitation.* 15(6). **669-677**
3. Yee, J. & Schulz, R. (2000) Gender differences in psychiatric morbidity among family caregivers: a review and analysis. *The Gerontologist.* 40(2). **147-164**
4. McCullagh, E., Brigstocke, G., Donaldson, N. & Kalra, L. (2005) Determinants of caregiving burden and quality of life in caregivers of stroke patients. *Stroke.* 36. **2181-2186**
5. Bugge, C., Alexander, H. & Hagen, S. (1999) Stroke patients' informal caregivers. *Stroke.* 30. **1517-1523**

6. Royal College of General Practitioners & Royal College of Nursing (2012) *Matters of life and death: helping people to live well until they die.* Retrieved from: http://www.rcgp.org.uk/clinical-and-research/toolkits/~/media/Files/CIRC/Matters%20of%20Life%20and%20Death%20FINAL.ashx
7. Prenner, J., Halperin, L., Rycroft, C., Hogue, S., Liu, Z., Seibert, R. (2015) Disease burden in the treatment of age related macular degeneration: findings from a time-and-motion study. *American Journal of Ophthalmology.* 160(4). **725-731**
8. Gohil, R., Crosby-Nwaobi, R., Forbes, A., Burton, B., Hykin, P. & Sivaprasad, S. (2015) Caregiver burden in patients receiving Ranibizumab therapy for neovascular macular degeneration. *PLOS one.* Doi: 10.1371/journal.pone.0129361
9. Glen, F. & Crabb, D. (2015) Living with glaucoma: a qualitative study of functional implications and patients' coping behaviours. *BMC Ophthalmology.* doi: 10.1186/s12886-015-0119-7
10. National Institute for Health and Care Excellence (2009) *Glaucoma: Diagnosis and Management.* Retrieved from: http://www.nice.org.uk/guidance/CG85/chapter/1-Guidance#provision-of-information
11. Sullivan, T. (2007) The Modified Caregiver-strain Index. *Try This: Best Practice in Nursing and Care to Older Adults.* 14 (1).
12. Robinson, B. (1983) Validation of a caregiver strain index. Journal of Gerontology. 38(3). **344-348**
13. Teasdale, T, Emslie, H., Quirk, K., Evans, J., Fish, J. & Wilson, K. (2009) Alleviation of carer strain during the use of the NeuroPage device by people with acquired brain injury. *Journal of Neurology, Neurosurgery and Psychiatry.* 80. **781-783**
14. Donnelly, M., Anderson, L. Johnston, B., Murray, R, Murphy, S., Comber, H., McGuigan, J., Reynolds, J. & Murray, L. (2008) Oesophageal cancer: cancer strain and mental health. *Psycho-oncology.* 17. **1196-1201**
15. Euroqol EQ-5D. Retrieved from: http://www.euroqol.org/about-eq-5d/valuation-of-eq-5d/references.html
16. Bowling, A. & Ebrahim, S. (2005) Handbook of health research methods. Investigation, measurement and analysis. Open University Press, Maidenhead. UK.
17. Saunders, L., Russell, R. & Crabb, D. (2012) Practical landmarks for visual disability in glaucoma. *British Journal of Opthalmology.* 96(9). **1185-1189**
18. Kitzinger, J. (1995) Qualitative Research: Introducing focus groups. *British Medical Journal.* 311(7000). **299-302**
19. Glen, F., Baker, H. & Crabb, D. (2014) A qualitative investigation into patients' views on visual field testing for glaucoma monitoring. *BMJ Open.* 4(1).
20. Tong, A., Sainsbury, P. & Craig, J. (2007) Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 19(6). **349-357**
21. Pope, C., Ziebland, S. & Mays, N. (2000) Qualitative research in health care: Analysing qualitative data. *BMJ: British Medical Journal*. 320(7227). **114**

22. Saunders, L. J., Russell, R. A. & Crabb, D. P. (2012) Practical landmarks for visual disability in glaucoma. *British Journal of Opthalmology.* 96(9). **1185-1189.** doi:10.1136/bjophthalmol-2012-30182

Appendix 2 – Participant Information Sheet (Chapter Four)

PARTICIPANT INFORMATION SHEET

Date and version: 08/05/2017_v2.0

Study Team

Principal Investigator	Professor David Crabb [1]
Clinical Investigator	Ms Lydia Chang [2]
Research Team	Ms Leanne McDonald [1]
	Ms Paula Turnbull [2]
	Ms Manjo Doug [2]

1. City, University of London 2. North West Anglia NHS Foundation Trust

1. Study title

Taking the strain? Impact of glaucoma on patient's informal caregivers.

2. Invitation

We invite you to take part in a research study. Before you decide if you want to take part, we would like you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. Please discuss this information with your family and friends if you wish. Participation is voluntary; it is entirely up to you if you want to take part in the study. Not taking part in this study will not affect your care in the clinic.

3. What is the purpose of the study?

We want to know more about the informal care you receive as a person with glaucoma. This informal (unpaid for) care could be given to you by a spouse, partner, relative or a friend.

4. Do I have to take part?

No. Whatever you decide to do will not affect your care within the NHS. If you do decide to take part, you will be asked to send back the questionnaire materials as an indicator of your consent.

5. What will happen to me if I take part?

You will be asked to complete the attached short questionnaire pack. It should take only 10-20 minutes to complete. The questionnaire pack contains:

- Questions about you – your age, education level and marital status.
- A few questions about your general health.

Your clinical team may also take a look at your medical records for more information about your health; this will be collected by your clinical team and stored securely.

If you have somebody that informally helps you with your glaucoma:

You will be asked to give a copy of the questionnaire materials to this person. This could be a spouse, a partner, a relative or friend who helps you with any aspect related to your glaucoma. This person will have a separate information sheet and consent form to sign and some additional questionnaires to fill in. You will then be asked to send back both questionnaires to us.

If you do not have somebody that helps you with your glaucoma

You will be asked to send just your questionnaire, plus the additional materials, back to us.

6. What do I have to do?

Once you have read this participant information sheet, you can fill in your questionnaire pack. This pack comes with a stamped addressed envelope to send the materials back to the researchers. By posting your materials back to us, you will be consenting to take part in the study. If you do not send your materials back, we will assume that you do not wish to take part in the study.

7. Are there any possible disadvantages/risks of taking part?

No – although some people may feel that the subject material is of a sensitive nature and discussing the subject of care may upset you. If you feel upset, you can contact the researchers to discuss this.

8. What are the possible benefits of taking part?

Participants will receive no direct benefit from taking part. However, it is hoped that the results of the study will be used to inform better support for patients and caregivers in the future.

9. What if there is a problem?

If you wish to make a complaint, you should contact the research team immediately.

- Paula Turnbull: North West Anglia NHS Foundation Trust.
- Tel: 01480 363880 or email: paula.turnbull@nhs.net

Usual NHS complaint mechanisms are also available to you:

- Patient Advice and Liaison Service (PALS) Tel: 01480 428964
  Open from 9am-4.30pm Mon to Fri or email: hch-tr.pals@nhs.net

10. Will my taking part in the study be kept confidential?

All information collected throughout the course of the study will be processed and stored securely using password protected systems. Your personal information will be coded and only other researchers who are part of the study will be able to identify you. When the study is over, copies of

your questionnaire results will be retained for the minimum period of ten years but will be anonymised. All data storage procedures in this study are compliant with the Data Protection Act 1998.

11. What will happen to the results of the research study?

The outcomes of this research will be published in an article in an open-access journal and will be presented at research meetings. Identities of participating volunteers will not be revealed in any published materials.

12. Who is organising and funding the study?

The study is being organised by North West Anglia NHS Foundation Trust and The Crabb Lab at City, University of London. The study is funded by an unrestricted grant from Santen UK Ltd, but Santen UK Ltd will have no access to the data from the study.

13. Who has reviewed the study?

The East of Scotland Research Ethics Service REC 2, which has responsibility for scrutinising all proposals for research on humans, has examined the proposal and has raised no objections from the point of view of research ethics. It is a requirement that your records in this research, together with any relevant medical records, be made available for scrutiny by monitors from North West Anglia NHS Foundation Trust, whose role is to check that research is properly conducted and the interests of those taking part are adequately protected.

Thank you for your interest in taking part in the study. **You may keep this participant information sheet for your further information.**

Appendix 3 – Questionnaire packs (Chapter Four)

Dear sir/madam

You are a very important person; you meet the criteria for our research because you have a diagnosis of primary open angle glaucoma and are seen by doctors at North West Anglia NHS Foundation trust.

We are a team of researchers at City, University of London and North West Anglia NHS Foundation trust working with Miss Lydia Chang, Consultant Ophthalmic Surgeon. We are interested in the health and needs of glaucoma patients and their family/friends. We invite you to take part in a research study. We have included a detailed information sheet about the research with this letter.

We aim to find out how glaucoma patients and their families/friends cope outside of a hospital environment. We hope to use the information from the study to improve resources for the loved ones of people with glaucoma.

If you choose to take part in the research, you will be asked to fill in some questionnaires and to give some questionnaires to a person who you feel helps you with your glaucoma. **This person can be a spouse, partner, friend or any other person who is not a paid professional. The person might, for example, help you with things such as attending appointments, putting in eye drops or anything else to do with your glaucoma.** You should give this person the green booklet.

If you do not feel that you have anybody who acts as an informal caregiver, you can still take part in the research. Simply complete the yellow booklet and send it back to us on the return address above.

Please note that we do not have access to your name and contact details, this letter has been sent on our behalf.

Thank you for considering taking part in our study.

Yours sincerely,

The research team

Patient

Thank you for choosing to take part in our research study. Please tick one of the options below:

- ○ I have given the sheet marked **'caregiver'** to somebody who helps me with my glaucoma. Please indicate your relationship to the person below.

  _____.

- ○ I do not have anybody who helps me with my glaucoma.

Section 1.

We would like to ask you some questions about yourself, please tick the circle that applies to you for each question.

Gender	**Ethnicity**
Male ○	White ○
Female ○	Asian/British Asian ○
	Black/African/Caribbean ○
	Mixed Ethnicity ○
	Other (please write) ○
Marital status	**Your education level**
Single ○	No School Education ○
Married ○	Secondary/High School ○
Committed relationship ○	Undergraduate ○
Divorced ○	Postgraduate ○
Widowed ○	Professional ○
Separated ○	

Section 2.

For this section, we would like you to fill in some questions about your health. Show us how you feel by ticking an option below.

1. **Mobility**

I have no problems in walking about	○
I have slight problems in walking about	○
I have moderate problems in walking about	○
I have severe problems in walking about	○
I am unable to walk about	○

2. **Self-care**

I have no problems washing/dressing myself	○
I have slight problems washing/dressing myself	○
I have moderate problems washing/dressing myself	○
I have severe problems washing/dressing myself	○
I am unable to wash/dress myself	○

3. **Usual activities (e.g. work, study, housework)**

I have no problems with usual activities	○
I have slight problems with usual activities	○
I have moderate problems with usual activities	○
I have severe problems with usual activities	○
I am unable to complete usual activities	○

4. **Pain/discomfort**

I have no pain/discomfort	○
I have slight pain/discomfort	○
I have moderate pain/discomfort	○
I have severe pain/discomfort	○
I have extreme pain/discomfort	○

5. **Anxiety/depression**

I am not anxious or depressed	○
I am slightly anxious or depressed	○
I am moderately anxious or depressed	○
I am severely anxious or depressed	○
I am extremely anxious or depressed	○

Thank you for completing this questionnaire

Further research invitation

We are planning to conduct more research in the future. This will involve coming to the hospital to take part in a focus group about the material discussed in this research. Please indicate below (by ticking an option) whether you would like to be contacted about this research.

Please don't contact me about further glaucoma caregivers research ○

I would like to be contacted about further glaucoma caregivers research ○

If you would like to be contacted, please leave your contact details below:

Name: _____

Telephone number: _____

Email address: _____

This is to be given to a person who helps with your glaucoma. Please do not fill this section in if you are the person this letter has been addressed to.

Dear sir/madam,

You are a very important person; you meet the criteria for our research because you have a family member or friend with a diagnosis of primary open angle glaucoma and are seen by doctors at North West Anglia NHS Foundation trust. You have been identified by this person as a suitable person to take part in our research.

We are a team of researchers from City, University of London and North West Anglia NHS Foundation trust. We are interested in the health and needs of glaucoma patients and their families/friends and we are contacting you to invite you to take part in a research study.

We aim to find out how glaucoma patients and their families/friends cope outside of a hospital environment. We hope to use the information from the study to improve resources for the family and friends of people with glaucoma.

We have included a detailed information sheet about the research with this letter; together with the questionnaire materials that we would like you to fill in.

If you choose to take part in the research, you will be asked to fill in some questionnaires and send them back to our research team. If you don't want to take part in the research, please return these materials to us at the return address.

Thank you for considering taking part in our study.

Yours sincerely,

The research team.

Caregiver

Thank you for choosing to take part in our research study. You have been identified as somebody who voluntarily helps a patient with aspects related **to their glaucoma** (e.g. attending appointments, providing assistance with eye drops).

Section 1.

We would like to ask you some questions about yourself, please tick the circle that applies to you for each question.

Gender	**Ethnicity**
Male ○ Female ○	White ○ Asian/British Asian ○ Black/African/Caribbean ○ Mixed Ethnicity ○ Other (please write) ○
Marital status	**Your education level**
Single ○ Married ○ Committed relationship ○ Divorced ○ Widowed ○ Separated ○	No School Education ○ Secondary/High School ○ Undergraduate ○ Postgraduate ○ Professional ○

What is your relationship to the patient? _____

Caregiver

Section 2.

For this section, we would like you to first complete some questions about **your** general health; not just related to your glaucoma role. Show us how you feel by ticking an option below.

1. **Mobility**

I have no problems in walking about	○
I have slight problems in walking about	○
I have moderate problems in walking about	○
I have severe problems in walking about	○
I am unable to walk about	○

2. **Self-care**

I have no problems washing/dressing myself	○
I have slight problems washing/dressing myself	○
I have moderate problems washing/dressing myself	○
I have severe problems washing/dressing myself	○
I am unable to wash/dress myself	○

3. **Usual activities (e.g. work, study, housework)**

I have no problems with usual activities	○
I have slight problems with usual activities	○
I have moderate problems with usual activities	○
I have severe problems with usual activities	○
I am unable to complete usual activities	○

4. **Pain/discomfort**

I have no pain/discomfort	○
I have slight pain/discomfort	○
I have moderate pain/discomfort	○
I have severe pain/discomfort	○
I have extreme pain/discomfort	○

5. **Anxiety/depression**

I am not anxious or depressed	○
I am slightly anxious or depressed	○
I am moderately anxious or depressed	○
I am severely anxious or depressed	○
I am extremely anxious or depressed	○

Caregiver

Section 3.

Think about the help that you give to your family member or friend **for their glaucoma.**

We would like you to think about how each statement applies to your **caregiving for glaucoma**.

Please tick the box that is most appropriate. Remember it applies to your **caregiving for glaucoma**.

My sleep is disturbed by my caregiving

		
Regularly ○	Sometimes ○	Not at all ○

Caregiving is inconvenient

		
Regularly ○	Sometimes ○	Not at all ○

Caregiving is a physical strain

		
Regularly ○	Sometimes ○	Not at all ○

Caregiving is confining/restricting

		
Regularly	Sometimes	Not at all

There have been family adjustments because of my caregiving

		
Regularly	Sometimes	Not at all

There have been changes in personal plans because of my caregiving

		
Regularly	Sometimes	Not at all

There have been other demands on my time (for example, other family members need me) which I have been unable to deal with

		

Regularly	Sometimes	Not at all

There have been emotional adjustments because of my caregiving

		
Regularly	Sometimes	Not at all

Some behaviour is upsetting (the person I care for has upsetting behaviours)

		
Regularly	Sometimes	Not at all

It is upsetting to find the person I care for has changed so much from his/her former self

		
Regularly	Sometimes	Not at all

There have been work adjustments because of my caregiving

		
Regularly	Sometimes	Not at all

My caregiving is a financial strain

		
Regularly	Sometimes	Not at all

I feel completely overwhelmed by my caregiving

		
Regularly	Sometimes	Not at all

Thank you for completing this questionnaire.

Further research invitation

We are planning to conduct more research in the future, which involves coming to the hospital to take part in a focus group about the material discussed in this research. Please indicate below (by ticking an option) whether you would like to be contacted about this research.

Please don't contact me about further glaucoma caregivers research ○

I would like to be contacted about further glaucoma caregivers research ○

If you would like to be contacted, please leave your contact details below:

Name: _____

Telephone number: _____

Email address: _____

Appendix 4 – Semi-structured interview schedule (Chapter Five)

The semi-structured interview schedule used in Chapter Five of this thesis.

Area of interest	Example questions/prompts
Caregiving role	**I would first like to know what kind of help each of you consider as part of the role of a caregiver?** Probes: If eye drops/hospital appointments/driving not mentioned; does anybody consider _____ as part of your role? If not, why not?
Experience of caregiving	**Has your experience with glaucoma changed the way you communicate with your loved one(s) in any way?** Probes: Tell me more about that. Was this a positive experience or a negative experience? Why? **Which areas do you feel that a caregiver/patient may need support in?** Probes: Why do you say that? What do you find particularly hard about that? What feelings are associated with that activity/role?

Support for caregivers/patients	**Are you aware of, or do you access, any support groups? What are your experiences with these?** Probes: Why? If not, why not? What makes this successful?