

# Research Updates

## PROJECT EVALUATION:

Evaluation of an Expert Patient Programme (EPP) for Patients with Chronic Primary Open Angle Glaucoma.

## PROJECT LEAD:

Professor Carol L. Cox, PhD, MSc, MA Ed, PG Dip Ed, BSc (Hons), RN FAHE, Associate Dean for Research and Enterprise, School of Health Sciences, City University London.

## RESEARCH FELLOW:

Raed Amro, Doctoral Candidate, School of Health Sciences, City university London and Emergency Nurse Practitioner, Accident and Emergency, Moorfields Eye Hospital, NHS Foundation Trust, Moorfields Eye Hospital NHS Foundation Trust.

This project follows on from a project that incorporated public and patient involvement in assisting patients, with chronic open angle glaucoma (COAG) to improve self-management of their disease so that their vision can be sustained. It complies with recommendations put forward by the Department of Health and the Darzi Report, *Our NHS, Our Future* (2008). The development and implementation of the research has been completed. An action research model has been employed that has been used in research projects associated with

arthritis and other diseases but not with patients who have ophthalmic disease. The evaluation component of this project is intended to inform future policies and practices that improve self-management of COAG and therefore enhance self-efficacy and the patient experience of health care. A report will be submitted to the International Glaucoma Association upon completion of the evaluation.

The Department of Health 'NHS and Social Care Model' has been established to improve care that enhances the lives of patients with long term conditions (DOH, 2005). Chronic diseases have become a national priority, as the care of people with chronic disease uses 78% of all NHS resources and 60% of hospital beds. Therefore it is essential for critical resources to be directed toward managing chronic disease in an efficient and cost effective manner.

The Department of Health's Health Strategy White Paper 'Saving Lives (1999)' announced plans for the establishment of an EPP as a new government initiative to assist people with long term conditions maintain their health and improve their quality of life through a self-management course led by someone who has a similar long term health condition. Self-management programmes have

# Research Updates

been operational in the USA since the 1970s and have been adopted in the UK since 1994 (DOH, 2005). The primary aim is not to impart medical information but to facilitate the development of self-management skills such as goal setting and problem solving.

In brief, the EPP has been designed through an action research model to help people with a chronic or long-term illness regain as much control over their physical and emotional well-being as possible (Squire and Hill, 2006). It complements existing health care programmes and treatments, empowering patients to be more informed and better able to develop partnerships with their medical practitioners. It has drawn upon the principles of public and patient involvement and underpinned by theories of working with and engaging people utilizing collaborative; participatory approaches. Action research is a vital, dynamic and relevant approach that has been demonstrated as enhancing change. It is argued that this method is a way to bring about sustainable services that evoke human flourishing (Koch and Kralik, 2006).

The development and implementation phases of the research have been completed. These phases have

identified issues that influence and affect Expert Patients in providing self-management skills for patients with COAG. It has involved systematic study of self-management programmes designed and delivered by Expert Patients to chronically ill patients, selection of an appropriate model for implementation and delivery of the model by five Expert Patients to patients (N = 25) with COAG. The final phase of the research will involve evaluation of the usefulness and effectiveness of the EPP to patients with COAG.

## STUDY METHODOLOGY

### For the evaluation:

The evaluation component of this project will involve assessment of knowledge, adherence, motivation and satisfaction. An overall outcome of the evaluation will be an indication of patient quality of life (QoL). Whilst health professionals find this measure difficult to quantify, it is an important issue in relation to a patient's ability to self-manage their COAG.

### Sample:

The following groups of patients will be assessed in the evaluation phase of the project:

# Research Updates

- 👁️ **Expert Patient Group:**  
Four Patients that received training and delivered the intervention.
- 👁️ **Intervention Group:**  
25 newly diagnosed glaucoma patients that were recruited and received one-to-one sessions with the Expert Patients on their second visit to the clinic and followed up on 1 month and 6 months post intervention.
- 👁️ **Control Group:**  
25 newly diagnosed patients attending the same clinics that have received the usual care and no intervention and followed up on 1 month and 6 months post recruitment.

## Inclusion and Exclusion Criteria:

Inclusion criteria for the Expert Patient:

- a) Have POAG - > 5 years
- b) Are aged 40 years or more
- c) Can complete a questionnaire and comply with instructions
- d) Agree to sign the consent form
- e) Have a score of 30 or more on the self-management questionnaire
- f) Have the confidence and experience to take an active role in choosing and approaching recruits for involvement in the study

- g) Have the time and confidence to read research proposals and plans
- h) Are able to access the views of a wide range of people and to reflect them.

## Exclusion criteria:

- a) Difficulty understanding English as a first language
- b) Other ocular pathology Less than 40 years of age
- c) Unable to fully understand and comprehend the consent form or to achieve a score of 30 on the self management questionnaire.

## Inclusion criteria for Intervention and Control Groups:

- a) Have POAG – newly diagnosed
- b) Are aged 40 years or more
- c) Sign the consent form
- d) Agree to be interviewed by the research fellow to obtain essential demographic information and complete questionnaires
- e) Agree to be contacted on the next visit or by phone twice “one month and three months after the initial contact” for monitoring purposes.
- f) Agree participate in a semi-structured interview.

# Research Updates

## Exclusion criteria:

- a) Difficulty understanding the English language
- b) Unable to fully understand the consent form
- c) Likely to be leaving the country in the next 12 months.

## Data Collection Plan:

Both qualitative and quantitative data will be obtained from the three groups. Health outcomes to be measured will involve the use of internationally validated inventories (questionnaires).

Qualitative Data: Expert Patient, Intervention Group and Control Group views will be obtained through semi-structured interviews conducted by the research fellow. Data will be coded and entered on a secured database. Expert Patients, Intervention Group and Control Group participants will be assigned a unique identification number (not their hospital number) so that information obtained can't be attributed to any individual participant.

## Interviews

- Expert Patients Interviews (N = 4) on the training programme and the EPP delivered to the Intervention Group

- Intervention Group Interviews (pre 10, post 10)
- Control Group Interviews (10).

## Quantitative Data:

The following will be measured:

- 1) Knowledge: 29 True & False questions to assess level of understanding regarding their disease.
- 2) Adherence: self reported scale of 0 to 10 representing how many times patients missed their eye drops in last 4 weeks.
- 3) Motivation/Satisfaction: on a scale of 1 to 5 patients will score their level of motivation/satisfaction on the following:
  - Effectiveness of treatment received (3Qs)
  - Convenience of treatment given (3Qs)
  - Ease of administration of their eye drops (3Qs)
  - Side effects of treatment prescribed (3Qs)
  - Eye appearance (3Qs).

Statistical data will be calculated through utilisation of SPSS 18.

Descriptive and inferential statistics will be determined at:

## Baseline

- (Expert Patients (n=4), Intervention Group (n=25) and Control Group (n=25))

# Research Updates

- \* Demographic questionnaire
- \* Glaucoma knowledge questionnaire
- \* Satisfaction questionnaire
- \* Glaucoma adherence questionnaire

First Follow Up (1-3 months)  
(Intervention and Control Groups):

- \* Glaucoma knowledge questionnaire
- \* Satisfaction questionnaire
- \* Glaucoma adherence questionnaire

Second Follow Up (6 months)  
(Expert Patients, Intervention and Control Groups):

- \* Glaucoma knowledge questionnaire
- \* Satisfaction questionnaire
- \* Glaucoma adherence questionnaire

## TIMETABLE:

Final evaluation write up of the project is planned for completion in December 2012.

## PROJECT:

Correlating visual deficits in the magnocellular, parvocellular and koniocellular pathway with in-vivo LGN activity in glaucoma

## PRINCIPAL INVESTIGATOR:

Anshoo Choudhary, Consultant Ophthalmologist and Honorary Senior Lecturer, Department of Eye and Vision Science, University of Liverpool.

## CO-INVESTIGATORS:

Dr Sophie Monika Wuerger, Reader in Visual Neuroscience, School of Psychology, University of Liverpool  
Dr Laura Michelle Parkes, Lecturer in Neuroimaging, School of Cancer and Imaging Sciences, University of Manchester

## RESEARCH ASSISTANT:

Miss Joanne Powell

As we are all well aware, glaucoma is a major cause of visual impairment and blindness in the UK and across the rest of the world. It causes this damage by destroying the nerve fibres that make up the optic nerve (the nerve that transmits the visual signals from the eye to the brain), but it is also associated with damage in the lateral geniculate nucleus (LGN) and the visual cortex (which are parts of the brain itself). There are three visual pathways; magnocellular, parvocellular, and koniocellular which link to separate layers in the LGN and these are altered in glaucoma, resulting in loss, shrinkage,

# Research Updates

or reduced activity of neurons in LGN and in the visual cortex. The koniocellular pathway seems to be especially effected in the early stages of glaucoma. These visual pathways can be behaviourally isolated by using chromatic modulations and their retinotopic organisation in the LGN mapped with high-resolution functional magnetic resonance imaging (fMRI).

Virtually nothing is known about the functional effects of primary open angle glaucoma (POAG) on LGN activity in humans and, in particular, how the signal changes in the LGN are correlated with clinical measures and behavioural deficits. The aim of this project is to correlate the visual deficits in the three main visual pathways with the activity in the LGN layers associated with these pathways in relation to normal, ocular hypertensive and glaucoma patients.

An International Glaucoma Association Research Grant was awarded in January 2011. The post of research assistant was created for the project and Miss Joanne Powell commenced work in September 2012. Because this was a clinical study involving glaucoma patients Miss Powell had to apply for a NHS passport and be Good Clinical Practice (GCP) trained.

Moreover it took some time to receive ethics from the National Research Ethics Service (NRES) (obtained October 2011) and local Research and Development (obtained January 2012).

This is a novel concept not routinely used in testing glaucoma patients. The first few months were spent in standardising the software for clinical use and there were problems about facilities. However, these were resolved and recruitment of patients to the trial was finally commenced in May 2012. 11 patients have been recruited to date and it is hoped that we will be able to recruit 20 more patients over the next 2 months. fMRI will be performed on 10 patients. It is envisaged that there may be teething problems with the fMRI as the concept is novel and the experiments may need modification based on our experience.

# Questions and Answers

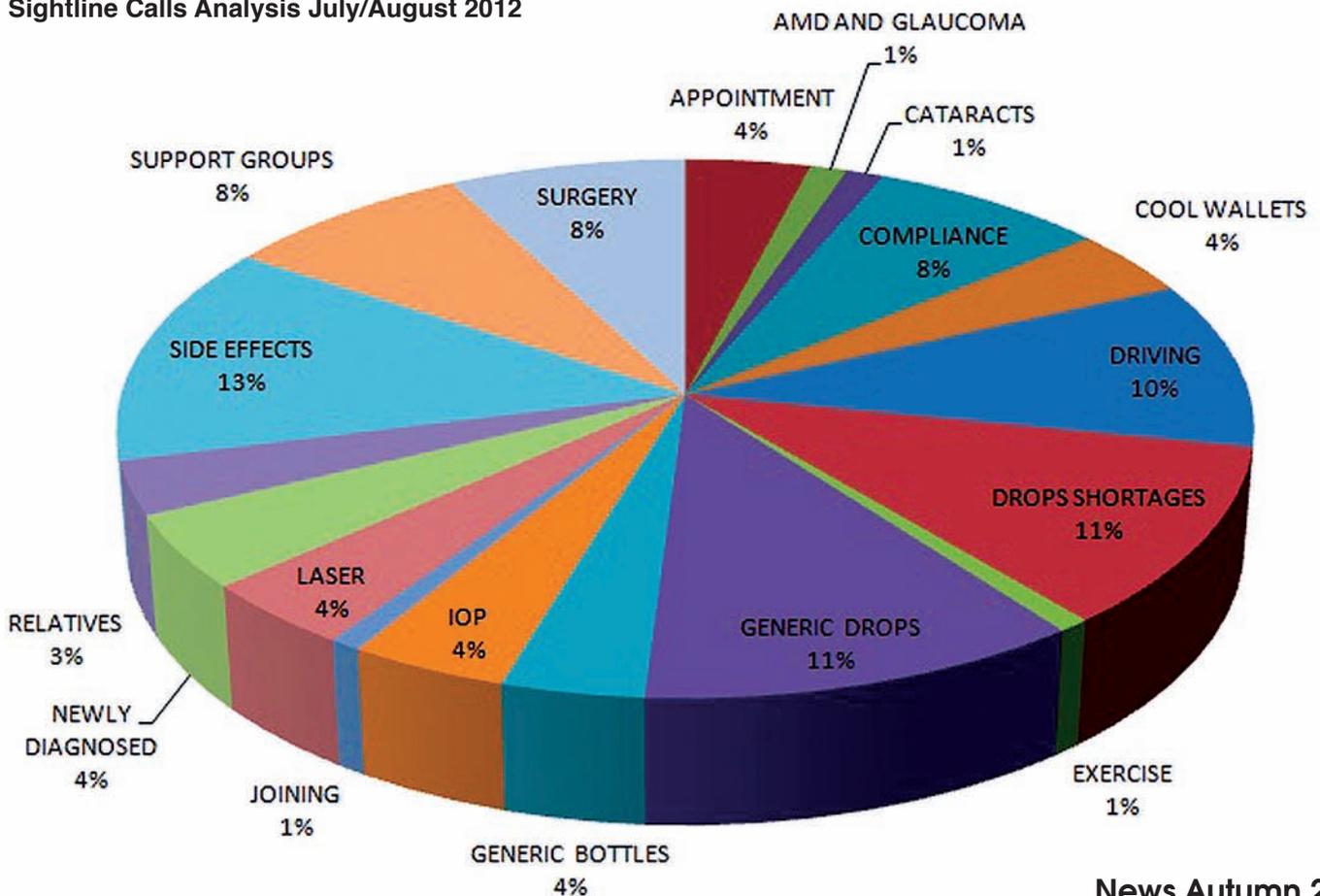
Traditionally we report the questions and answers from the preceding IGA meeting in each edition of IGA News, but very often these questions are based on the lectures that have been given at the meetings so they aren't always of general interest. On this occasion, there having been no meeting since the Janice Krushner Memorial Lecture in March, we are basing this section on the most commonly asked questions of the Sightline Team here at IGA HQ.

## Generic Eye Drops

The largest proportion of questions to Sightline in July and August were

about generic eye drops (15%). Many of the questions were about the fact that people were receiving different bottles when compared with their earlier prescriptions (particularly if they use Xalatan) and they were concerned that there might have been a mistake with the prescription at the pharmacy. Xalatan (manufactured by Pfizer) is no longer patented and because of this other companies are now permitted to produce latanoprost (the generic name for Xalatan) usually at a much lower price to the National Health Service than was the original drop. The vast majority of prescriptions written by doctors in the NHS are for generic medications and

Sightline Calls Analysis July/August 2012



# Questions and Answers

in most cases these generic products do just as good a job as did the original drug.

All generic medications have to be 'bioequivalent' to the original drug, but there can be differences in concentration (within specific limits) and there are often differences in packaging and in the look of the drug – just think about the number of different shapes and sizes that simple aspirin tablets come in these days!

However, if you, as an individual, find that the new generic latanoprost doesn't suit you as well as did Xalatan, perhaps because you use a Xalease compliance aid or perhaps because it is less comfortable in the eye, or for some other reason, it is possible for a doctor to prescribe the original, non generic, Xalatan (or any of the other glaucoma eye drops that are now commonly supplied in generic form) for you on a case by case basis, so don't hesitate to speak to your ophthalmologist or your family doctor and explain any new problems you may be having with the generic medication.

## **Surgery and Laser**

Taking these two subjects together under the group title of non medical (non drug) ways to control intraocular

pressure (IOP) account for some 12% of our Sightline calls. Of course, there are some calls that are very complicated where the caller has many different factors to take into account when considering laser or surgery, but the vast majority of calls are from people who are worried about their surgery or laser procedure, many of whom start by saying 'I know I'm being silly, but...'

Believe me when I tell you that they are not being silly! Indeed, even here at the IGA we have a colleague who has witnessed, first hand, many eye operations who still states with complete conviction that, if they need an eye operation they will have to have a general anaesthetic! For most people who have had a laser procedure or glaucoma surgery, looking back, they wonder why they were worried at all and, if they need a second procedure then they are much less worried, but for those people contemplating laser or surgery for the first time it is entirely normal and natural to be worried about the prospect.

The truth is that the idea of surgery is far worse than the reality, but the fact that the surgeons and hospital staff do it all the time can make them seem just a bit off hand on occasion. It is important to know what is going

# Questions and Answers

to happen to you on the day and what is going to happen after your operation. The modern necessity of highlighting everything that might go wrong doesn't help with confidence, but the truth of the matter is that these complications are very rare indeed (although no one can guarantee a perfect experience in every case).

Whether you are having laser or surgery, a local or general anaesthetic, the truth is that the worst part of the whole thing is usually having the anaesthetic and that really isn't much worse than having an injection or perhaps a blood test. None of us like them, but they really aren't too bad. People often worry about seeing the surgeon coming at them with a scalpel, especially if they are having a local anaesthetic, but the truth is that the eye not having the operation is covered during the procedure and the eye being operated on has drops that dilate the pupil so much that you can't see anything of what is going on. Most people describe what they see as a bit like a Kaleidoscope of lights, but no scalpels or anything else. In many cases you will hear music, because a lot of surgeons like to have music while they work and you will always have a nurse right by you so that if you feel uncomfortable you can let her know.

Laser and surgery is never recommended unless there is good reason and the balance of risk and benefit is firmly on the side of a non medical intervention, but it is never silly to be worried and the only silly question is the one you don't ask. If you would like to talk to a Sightline operator about your operation (either in the future or in the past) don't hesitate to call on 01233 64 81 70.

## **Driving:**

10% of our calls are about driving with glaucoma and many are very sad cases where people have had to stop driving. Details of the required standards are available from Sightline (ask for the driving leaflet), but above all, if you have glaucoma in both eyes, please don't delay in informing the DVLA – driving with glaucoma is perfectly safe if you meet the visual standard – not informing the DVLA and continuing to drive is not only illegal, it may be dangerous because you won't necessarily be aware of damage in your field of vision that may hide a child or animal coming into your path, and I'm sure that none of us would willingly take that risk!