Patient views on visual field testing for glaucoma monitoring

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Competing Interest Statement

None of the authors have any competing interests in relation to this work.

Contributions of authors

FCG: Conducted data analysis, and wrote and edited the manuscript (joint first author).

HB: Conducted focus groups and data analysis, and wrote the manuscript (joint first author).

DPC: Conceived and designed study, and reviewed and edited the manuscript.

Abstract

Objectives: To investigate the views and experiences of patients regarding their glaucoma follow-up, particularly the type and frequency of visual field (VF) testing.

Design: A qualitative investigation using focus groups. The group discussion used broad open questions around the topics in a prompt guide relating to experiences of glaucoma follow-up, and in particular, VF monitoring. All groups were taped, transcribed and coded using manual and computer aided methods.

Setting*:* Three NHS hospitals in England; two focus groups took place at each hospital.

Participants*:* Twenty-eight patients (mean [SD] age: 74 [9] years; 54% female) diagnosed with glaucoma for at least 2 years. Each focus group consisted of 3-6 patients.

Primary and Secondary Outcomes:

1) Gather information regarding patient views about their glaucoma follow-up care, with a particular focus on VF monitoring.

2) Identify areas of importance from the patient's perspective for successful follow-up.

Results: Whilst patients expressed a general dislike for the VF test, they recognised the importance of regular monitoring for preserving their vision. Patients would be open to more frequent VF testing if the clinician felt it would enhance their care. Nevertheless, a number of themes recurred throughout the focus groups representing perceived barriers to follow-up care. The testing environment, patient-doctor communication, waiting times, efficiency of

appointment booking and travel to the clinic were all perceived to influence the general clinical experience and the quality of assessment data.

Conclusions: Patients trust the clinician to make the best decisions for their glaucoma follow-up. However, patients highlighted a number of issues that could compromise the effectiveness of research-supported guidelines for frequency of VF testing. Addressing patient-perceived barriers could be an important step for devising optimal strategies for follow-up care.

Article Summary

Article Focus

- Glaucoma is a chronic and progressive eye disease and all diagnosed patients will require lifetime monitoring of their vision.
- Visual field (VF) testing is one of the most widely used assessments for glaucoma and places a large burden on NHS resources; research is needed to devise the most effective strategies for glaucoma VF monitoring.
- This study used focus groups to investigate patient views about VF testing in their follow-up care. Effective VF testing will require the confidence and cooperation of the patient.

Key Messages

- Although patients disliked VF testing, they accepted it as an important part of their vision assessment and disease management.
- Patients discussed a number of areas of perceived importance for VF monitoring, raising particular concerns about distracting testing environments, the quality of test

instructions, how results were explained to them and excessive pre-testing waiting times.

Strengths and Limitations of this study

- This is the first study to examine patient views of visual field monitoring using focus groups.
- Focus groups only took place at three selected hospitals - it is assumed that the views expressed represent the experiences of patients in a wider UK population.

Introduction

Glaucoma is a group of chronic diseases of the optic nerve that, if not managed effectively, could lead to visual impairment or blindness. Currently, the only modifiable risk factor for disease worsening (progression) in glaucoma is reduction of intraocular pressure (IOP). A variety of different approaches to IOP lowering are available, meaning surveillance of the patient is important in selecting the correct intensity of treatment. Nearly half a million people are thought to have the condition in England alone, receiving over a million outpatient visits annually[1]. Since the prevalence of glaucoma increases exponentially with age, these figures can be expected to increase dramatically with an ageing population. Glaucoma monitoring therefore represents a major workload for eye services in the National Health Service (NHS).

Assessment of non-seeing or 'blind' areas of the visual field (VF) is central to the monitoring of visual function in glaucoma. The VF is assessed by standard automated perimetry (SAP), a sophisticated automated instrument. The test is carried out in a darkened room and takes about 10 minutes per eye. In short, a patient looks into the part of the instrument that consists of a large semi-circular bowl covering their entire field of view. The instrument presents a series of stimuli (spots of light), one at a time, at a range of contrast levels at varying locations in the VF while the patient fixates on a central point. The patient responds by clicking a button when a stimulus is detected. This process yields a map of the seeing parts of the patient's field of view; this map is subjected to statistical analysis comparing a patient's results to normative values for people with healthy vision. Speed of VF loss varies considerably between treated individuals, so it is vital that the VF is monitored accurately and at appropriate intervals in order to preserve visual function[2]. The National Institute of Clinical Excellence (NICE) reported gaps in evidence regarding how best to monitor patients with glaucoma over time[1]. Guidelines proposed by the European Glaucoma Society (EGS) recommend that the

frequency of VF tests should be increased for newly diagnosed patients in order to better determine speed of VF progression. This notion is supported by research evidence which has indicated that three VF tests per year would be useful for identifying patients that are deteriorating at fast rates in the first 2 years of follow-up[3-5]. However, a recent audit of glaucoma clinics in England indicated that most patients only have about one VF test a year[6]. Furthermore, VF monitoring intervals assigned by clinicians (for hypothetical patient scenarios) are variable[7]. Many glaucoma specialists concede that better tracking of the VF would be helpful in managing patients but view it as impractical in the current health setting[7]. This finding suggests that personal attitudes regarding the frequency of testing could play an important role in translating research to practice.

The clinician ultimately drives decision-making based on their own estimates of the likelihood and speed of disease progression, but establishing effective monitoring strategies may also require the input of the patients themselves. Care plans that place burdens on patients may result in a reduced willingness to return for follow-up and compromise the quality of the data obtained that is subsequently relied on during management[8]. Anecdotal evidence suggests that patients dislike doing the VF test, and one study showed that patients rate the VF test least favourably of all the vision assessments[9]. However, no study has asked patients with glaucoma in detail about their perceptions of the VF test and their follow-up care.

When considering the patient's perspective of their health condition, many studies opt to use questionnaires to quickly gather information about the perceptions of service users. However, this method can be impersonal and restrictive, and patients may misinterpret the meaning of the question or simply not be given an appropriate opportunity to contribute their full opinion.

Qualitative techniques, such as focus groups, offer an alternative method of gathering information about not only what a patient thinks, but also how they think or why they may hold a particular view. Group interaction encourages participants to explore and clarify individual and shared perspectives and supports the participation of people who may be reluctant to contribute their views in a more formal one-to-one scenario[10].

For the first time, the current study aims to explore patient views and experiences of glaucoma monitoring via focus groups. One objective was to establish patients' views about VF testing.

Method

Participants and methods

Focus groups took place between May 2012 and January 2013 in the following locations: The Queen Alexandra Hospital NHS Trust in Portsmouth; Norfolk and Norwich University Hospital NHS Foundation Trust in Norwich; and Moorfields Eye Hospital NHS Foundation Trust in London. The study was multi-centred to reduce the bias that might come from one geographical area and to encompass healthcare trusts in both urban and rural locations. The sites were chosen because they were involved in a wider programme work, of which the current study was a component. There were two focus groups at each site, with participants randomly allocated to one of the two groups at the corresponding hospital.

The study used purposeful sampling whereby a consultant ophthalmologist at each participating eye hospital selected participants that were suitable for the study. To take part, the participant was required to be aged 60 years and over and to be an established glaucoma

patient who had been under review for at least two years. These criteria were chosen to ensure that participants had had sufficient experience of VFs as part of their glaucoma follow-up. One of the authors (HB) then telephoned patients who had given their permission to be contacted to invite them to take part in the study. Interested participants were subsequently sent further information by post.

A total of 28 participants (mean age [standard deviation] 74 [9] years; 54% female) took part across the six focus groups. Each group consisted of three to six patients and included participants of both genders.

Procedure

A topic guide was devised prior to beginning the study outlining question areas regarding general glaucoma care, leading on to more specific questions about experiences of the VF test and opinions about VF test frequency. Study topics were informed by an initial pilot exercise involving a discussion with two patients with glaucoma, who also provided additional verbal and written information about their experiences. Questions were broad, open and "non-leading". Prompts were used to introduce topic areas and encourage respondents to elaborate; however the onus was on the participants to supply the overall content of the discussion. If discussion went substantially off-topic, or one participant was dominating the conversation, the interviewer would reflect back to a previous topic and encourage other participants to contribute their views.

Prior to the study, participants were informed that they would be involved in "an open discussion about glaucoma care", but were unaware of the emphasis on VF testing frequency.

All focus groups were conducted by one of the authors (HB), a post-doctoral researcher who had prior experience of qualitative research involving patients with glaucoma[11, 12]. The interviewer and participants had no prior knowledge of each other in a clinical or personal context, so each focus group began with general introductions. Field notes were taken during the sessions to aid later interpretation of the data, although note-taking was purposely minimal so that the interviewer could be fully attentive to the discussion. The focus groups lasted between 60 and 75 minutes.

The study received approval from a NHS National Research Ethics Service (NRES) committee and was approved by research governance committees of the participating institutions. The study conformed to the Declaration of Helsinki and written consent from all participants was obtained prior to each focus group.

The study was designed and reported in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) for interviews and focus groups[13].

Analysis

All focus groups were audio-recorded (with permission from the participants). The dialogue from the recordings was later transcribed and reviewed by the investigators. Field notes were used to account for any information missed or incorrectly reported in the transcripts due to excessive background noise.

Data was analysed by two of the authors (HB and FCG) independently using the framework technique[14] displayed in Table 1. Each investigator read and re-read the transcripts and

manually identified the key themes from the data in addition to some example quotes to illustrate main points. One of the authors (FCG) was blind to the purpose of the study at the point of analysis. The qualitative software package NVIVO 10.2 (QSR International, Cambridge, Massachusetts) was used to organise the thematic framework by refining and condensing the predefined categories and to identify additional themes for exploration. Any differences of opinion regarding the meaning of sentences or the importance of themes were later discussed until a consensus was reached.

Table 1: Framework Technique used for data analysis (similar to that developed by the Independent Research body, Social and Community Planning Research, now the National Institute for Social Research[14])

Framework Technique		
1.	Familiarisation	Reading and re-reading the transcriptions
2.	Identifying a Thematic Framework	Condense data into categories
3.	Indexing	Codes systematically applied to the data
4.	Charting	Re-arranging the data according to the thematic content in a way which allows for a cross case and within case analysis
5.	Mapping and Interpretation	Interpretations and recommendations

Findings

Data was initially indexed according to themes central to the main research questions, such as opinions of the VF test, current experience regarding the frequency of VF testing and opinions about more frequent VF testing. Throughout the analysis a number of additional themes emerged, often with their own sub-themes; these generally related to specific areas perceived to affect the follow-up experience, and included points relating to clinical constraints (waiting times, booking appointments), travel to the clinic, the testing environment and aspects of patient-clinician communication. The themes and sub-themes are summarised in Figure 1.

Figure 1: Coding tree showing main themes and sub-themes that emerged from the analysis, and how the categories relate to each other.

Direct quotes taken from the transcripts are italicized. These quotes were chosen to illustrate the key themes that emerged from the focus groups. Excerpts are annotated with a pseudonym for the corresponding participant based on their gender ("M" or "F") and the order in which they spoke in the interview. The location of the focus group and the session number (1 or 2) are also shown for each quote.

Visual fields

Patients expressed a dislike for the VF test. They found the test time-consuming, old-fashioned and tiring.

Well the reason why I don't like them: I don't like the dark, I don't like confined spaces and I don't like having one eye closed and having to concentrate, even if it's for just a couple of minutes, because then my mind wanders… F1, Portsmouth 1

It seems a bit antiquated, pressing the buttons… it doesn't seem positive enough to me. F3 Norwich 2

Many put pressure on themselves to perform the test well, as they felt there could be a lot riding on their performance.

There is pressure: I think it is because your eyes are so important for everyday living, that, you know, you're frightened to [not do well]. F2 Portsmouth 1

There was a general appreciation that such testing was vital to preserve their vision.

Well… obviously I'm very grateful that I'm being monitored all… F4 London 1

….mine has been 10 years and you think, well how long will I have my sight? … My mum had lost her sight by then, you know… F3 Norwich 2

Patients found other tests used in their clinical monitoring, such as visual acuity, intraocular pressure measurement and imaging tests, less tiring and laborious. At the same time some patients felt the VF test was more 'valuable', providing more reassurance that their condition was being investigated.

[with] the [imaging] there's just one person, one machine and you, and it's done and that's it, it's over…within minutes. F3 Norwich 2

... they look in your eyes to measure your pressure but when you do that field test, they see more…. F1 London 2

Frequency of visual field testing

Current experience

VF tests were usually performed once or twice a year, either during or closely prior to the patient's general clinical appointment. Patients who visited the clinic more frequently would have a VF test at only some of their appointments. Some patients were often unaware as to whether they would have a VF test during their visit.

I mean they just say you're going to come for your next appointment in whatsoever, whatever time, but they don't say, 'Oh, in that time you will be having a visual field check', so that you know that you are going to have to be that little bit longer.. F2 Portsmouth 1

When patients were asked whether they would be willing to visit the clinic for VF testing more frequently, there was a reluctant agreement. The test was viewed as a '*necessary evil*' and most were open to more frequent testing if the clinician felt it would enhance their prognosis, although there was scepticism as to how useful the test actually was.

If it was necessary. F2 Portsmouth 2

You'd get on with it. M1 Portsmouth 2

If it helps the cause so be it. M2 Portsmouth 2

I don't want to lose my sight, I'd come in whenever. F2 Portsmouth 2

If it holds it back for 10 years… I'm happy with another 10 years! M1 Norwich 2

… I suppose I'd accept it because I would hope that the reason for asking me was that they will get more information from that, which obviously deals with the whole problem but…I'm not really sure at all about how useful they are. I mean is it just statistics or whatever? …I'm sure they're useful but I wonder in what proportion of use they are compared to, you know, looking in the eye and pressures and things….

F3 Norwich 2

Some patients associated more frequent testing with worsening vision; therefore being asked to attend for more testing could lead to increased anxiety.

… you'd think they've called me back 'cause it's going, deteriorating. But I mean if they said to do it, I've always done … because they're doing the best for me…

F3 Norwich 2

One recurrent topic regarding VF testing was issues relating to the learning effect, whereby performance improves with increased testing. Some suggested that more repeat testing would be helpful. However, the repeated tests may only be worthwhile if they took place at the beginning of their follow-up care.

...interestingly I went and did one once and they said to me, "this has improved from the last time" and I said "well I think I'm just getting better at computer games" ... I think you do know what's coming and you can improve and I just feel more comfortable with doing it.

F1 Norwich 1

I think to do a field test right at the beginning, and to take that as being the definitive field test is wrong...because I think you need to do a test and think, and revise it in your mind what you've done and then do it again. M1 Portsmouth 2

There was some debate about the period of time between VF tests.

I think you need to do a field test and then perhaps a month later do the second one.

M1 Portsmouth 2

Well not if you have a long gap between them. F1 Norwich 2

I've got used to it now. F2 Norwich 2

I don't think it's any different really. F3 Norwich 2

The idea was raised that routine VF testing could be carried out in a more convenient location. Some patients had previously visited a local optometrist to carry out a VF test for the purpose of assessing their legal fitness to drive. On the positive side, patients liked the convenience of doing so and described a better testing environment. Conversely, they questioned the competency of the staff, the quality of the equipment and the information trail back to the hospital.

The principle of having routine tests done locally is acceptable providing they are trained.

M1 London 1

I would be concerned about how often the machine was calibrated to get an accurate reading.

M2 London 1

Is the information going back to where it matters in my notes? Things do get lost, and will someone actually look at the test?

M1 London 2

Some felt they had built up a level of trust with the hospital eye service and would therefore prefer to have VFs conducted in this environment.

I've been here for quite a while now and I like coming to them: I don't want to go anywhere else. F1 London 2

I would feel the same because it's a matter of trust. M2 London 2

Perceived issues and barriers for successful follow-up care

Some additional themes emerged during the analysis, highlighting a number of areas perceived to be important and potentially representing barriers to successful follow-up.

Communication

Visual Field Instructions

Regardless of how long they had been attending the glaucoma clinic, patients appreciated having the VF test procedure fully explained to them. It was rare for a staff member to stay with the patient throughout the test, but on the occasions it did happen, patients found the experience reassuring and felt the encouragement helped their performance.

... They say, "Have you done this before?" You say "Yes". And that's it, you're left there and eventually they say, "Have you finished?

M1 Portsmouth 2

I had one about three weeks ago and it was a young nurse and it was a completely different experience. She was professional, polite, kind; she told me exactly what they were doing.... it was almost a pleasant experience. F1 Portsmouth 1

There was discussion about understanding aspects of the testing procedure and how the procedure was explained. For example, some patients expressed uncertainty and felt test pressure would influence their results. Again, explanation and reassurance before and after the test helped.

The staff told me: "don't worry about missing [a light] because it'll come later", so you know you get a second chance. F1 Norwich 1

... if in doubt press the button, don't you? F1 Portsmouth 2

Explanation of results

Most patients said they had to specifically enquire about their results to find out information about their vision and whether their condition had progressed since the last appointment. Some patients felt intimidated to ask the clinician for feedback as to how they had performed, feeling they were being a nuisance or wasting the clinician's time.

My wife always says "how did you get on?" and I say "I don't know", and that's one of the problems. M2 Portsmouth 2

I don't think they've got time to listen to you, or they don't appear to, and I don't know whether they would listen…. You feel pathetic asking these questions. F3 Portsmouth 1

It was felt that a better explanation of the test results after completing the VF would ease some of the pressure felt when performing the test.

IF THE DOCTOR ACTUALLY SPENT A BIT MORE TIME DISCUSSING IT WITH YOU, WOULD IT MAYBE EASE THE PRESSURE OF ACTUALLY DOING THE TEST?

Interviewer.

I would... M1 Portsmouth 1

I think possibly. F3 Portsmouth 1

Yes, I mean I would still panic, but if I knew, yes. F1 Portsmouth 1

Patients may be more inclined to have VF tests more frequently should they be informed clearly about what the results indicate about their prognosis.

I don't mind how many times I do it providing I get a result of the test at that time compared to what the previous one was. Is there any improvement? Is there any downgrade?

M1 Portsmouth 1

The patient-clinician relationship

The quality of relationship with the clinical staff and aspects of patient-clinician communication also emerged as key factors influencing perceptions of the follow-up process.

An apparent lack of personalised care caused unease: there was a sentiment that sometimes the clinician simply looked at the eyes and failed to consider the person's individual needs.

You're not a person, you know, you've just got eyes, they're just going to deal with that and that's it. F3 Portsmouth 1

The experience was seen to be much more bearable if they felt the staff member dealing with them was empathic.

Even buying a chop, you know: if the butcher's interested, it helps doesn't it?

M3 Norwich 1

The opportunity to spend more time with their consultant ophthalmologist was a key factor that influenced whether or not patients were open to visiting the clinic more frequently.

Not [just] for the field test... But I wouldn't mind coming in more to see the doctor.

M2 London 2

Testing environment

The testing environment was another important theme. The dark room, especially if it was warm, made focusing on the tests difficult. Patients felt they performed better in the morning when they were more alert. Ambient noise in the room made it difficult to concentrate; staff members talking and doing the test at the same time as several other patients all had deleterious effects.

I will also say that the staff chatter a lot, which is difficult for concentration; the doors open and close, there's a lot of noise. F1 Norwich 1

The times that I've had the visual field test done in a room where there's just one [machine], I felt more confident to do it; it was much quieter and more relaxed and it seemed to be a lot quicker too. F3 Norwich 2

I think having the quieter atmosphere would generally help I'm sure….just that feeling of slight calm, you can relax more and then it probably would be a lot quicker because maybe you're not going to miss as many [lights] as you haven't got other distractions. F3 Norwich 2.

Clinic constraints

Waiting times

Waiting times were a major concern at all locations. The standard time taken per visit was estimated to be two hours, although the wait was often unpredictable. Established patients were used to the wait and tried not to let it affect them but they still found the system frustrating. Patients were scared of missing their slots and, therefore, would not leave their seat in the waiting area.

No way I'm going to nip off ... especially as now I'm on my own, no way…. just even nipping off to the [bathroom] because you think, 'He's bound to call me. I can sit here for an hour and he'll call me the minute I go to the [bathroom]. F2 Portsmouth 1

Likewise, the waiting environment outside the clinic was viewed extremely unfavourably.

The first time I came in I thought, 'Oh my….' There were hundreds of people, it felt like hundreds, but we were all sat in a line. There's nothing on the walls. There's tiny writing on the notice board and you think, 'Hang on, we've all got eye problems in here, how are we supposed to read these signs?' The walls are just blank- it's a really miserable place, isn't it? F3 Portsmouth 1

Although it was repeatedly acknowledged that the clinics were very busy, which had the knock-on effect of increased waiting times, patients felt they were getting adequate treatment

overall. It was suggested that there was a trade-off between longer waiting times and higher quality treatment:

I think that's a very fair price to pay for the fact that you're being dealt with in a UK centre of excellence. There's a trade-off in that you're getting state of the art treatment but the price is you've got to sit around for it. M1 London 1

Travelling to the clinic

Several sub-themes emerged including issues with long distances to travel, avoiding rush hours, travel costs and travelling alone.

I think the problem is because I live nearly an hour away, for me the nearest hospital is an hour away… F2 Norwich 2

Taxi is the only way I can do it now. You know, I can get to the station by bus and possibly with help to get on the train but it's not easy…..It's horrific, frightening. M2 London 1

Tiring journeys to the clinic and late clinic appointments were also sometimes perceived to have a negative effect on VF test performance.

Scheduling appointments

The scheduling of appointments was a major concern: often the systems were so overbooked that patients were unable to make their next appointment at their clinic visit. Some were

asked to call to make an appointment six weeks before they were due to attend whilst others were sent an appointment in the post at a much later date.

You can only make an appointment six weeks in advance. You used to get a twelve month appointment letter just after you had been for an appointment; now its six weeks before you are due. M2 Norwich 1

Some patients had been asked to attend on a Saturday to reduce the back-log of appointments. The day was not seen as a problem although the standard of care was questioned.

I've been asked to come on a Saturday which is not a problem but the trouble is you never see anyone who can make a decision. I ended up seeing a retina man. So after a couple of visits I asked to be seen on a weekday by a glaucoma specialist." F1 Norwich 1

Often patients would receive an appointment only to have it cancelled a couple of weeks before the clinic was due to take place. This was not only frustrating to people who had made arrangements for their appointment, such as asking a friend to accompany them or arranging cover for sick spouses, it caused concern that their appointment was to be at a much later date than the clinician had originally requested.

"So if you've been given a six month appointment and it's cancelled, and you're not given another one, you ring up and then they say "oh we can't give you an appointment now until October". That was 10 months. Now if your consultant says 6 [months] and it's 10 and something's gone wrong with your vision in between, you have no way of telling." F2 Portsmouth 2

Patient recommendations

At the end of the groups patients were asked to recommend changes to improve their follow-up care. The recommendations were similar across all locations and the most popular suggestions are displayed in table 2.

Table 2: Patient recommendations for improving follow-up care.

Patient Recommendations	
1.	Less waiting and clinics running to time.
2.	Flexible booking and changing of appointments.
3.	To have a calmer, quieter environment in the visual field room with less people doing the test at the same time.
4.	To modernise the visual field test.
5.	To have more continuity of care by seeing the same clinician at each visit.
6.	To receive better communication from the clinician.

Discussion

Data from this study supports evidence from elsewhere that patients find VF testing more laborious and demanding than other vision tests[9]. Nevertheless, patients were willing to complete more VF tests on the guidance of their clinician, as ultimately they were prepared to do whatever it took to preserve their vision. Thus, patients may tolerate more frequent VF testing during the first two years of their follow-up care as recommended by the research literature[3, 4] and some clinical guidelines[15] . Patients commented that it took time to feel comfortable with the test procedure, and that multiple attempts were needed to gain an accurate representation of their vision. These viewpoints complement existing evidence showing that performance can improve considerably during follow-up due to gaining experience with the testing process[16].

There were, however, a number of additional themes that emerged from the data which identified areas that could represent potential barriers to successful glaucoma monitoring. Patients felt that the environment in which they completed the VF test was linked to how well they were able to perform the task, with staff members talking loudly, the number of people in the room, and the time of day all listed as important interfering factors. These views coincide with other evidence showing that the environment, the technician and the time of day do have a significant influence on measurement variability from VF tests[17]. Fatigue, a topic mentioned frequently throughout the discussions, has also been shown to affect performance as test duration increases[18].

Patients highlighted the importance of effective task communication for influencing their VF test performance. Prior evidence has shown that the quality of instruction given before the VF test can significantly affect subsequent estimations of VF defect severity[19, 20]. Patients also

felt that it was essential to have the task explained to them properly, even if they had been attending clinics for some time. Having a staff member in the room whilst they carried out the test was found to be reassuring. These findings reiterate the idea that ensuring that the task demands are communicated clearly and effectively before every VF test, and being on hand to alleviate any concerns or questions that the patient may have, may help maximise the quality of the data gained from the assessment[20-22].

Other discussion points relating to communication were also raised repeatedly throughout the focus groups. Patients felt that many clinicians treated them as an 'eye' rather than a person, with those staff members who took a more individualistic and empathic approach viewed favourably. Notably, patients felt that they had to ask explicitly about their results in order to learn details about their own condition. Evidence has shown that that the patient and clinician's views of their condition are not always aligned, which may be due to miscommunication or misinterpretation of key information on both parts[23]. By explaining the results in a clear, simple and concise manner, the patient will inevitably improve their understanding of their condition, which in turn could influence how well they respond to important aspects of their follow-up care. For instance, it has been shown that the way in which clinicians communicate with the patient can influence future adherence to medication[23]. Providing better information about the purpose of VF testing, what is required of the patient, and their results and general prognosis could be vital for improving attendance for VF tests or for the subsequent quality of data obtained. Perhaps developers of SAP ought to think about ways in which the complex measurement of the VF could be easily presented and communicated to patients. It is important to note that some patients associated more frequent testing with worsening vision, which caused some distress. Thus, should

patients require more frequent tests at some point in their care, it is also vital to involve the patient and explain reasons for the decision.

Excessive waiting times and difficultly booking appointments were also major concerns. In particular, patients worried that appointment cancellations could extend the interval between tests beyond what was recommended by the clinician, therefore leaving them exposed to undetected disease progression. It is known that whilst clinicians select appropriate monitoring intervals, hospital-initiated rescheduling is a major challenge to appropriate follow-up[6, 24, 25]. Moreover, it was typical for patients to wait at the clinic for hours in order to complete multiple vision tests, causing frustration and tiredness which some perceived to influence their subsequent performance. Potential solutions could involve conducting only the VF test during short independent appointment slots, or carrying out tests at a more convenient location. However, such strategies would involve further investigation as to their overall cost-effectiveness and should address other associated practicalities such as travel (a significant contributor to total patient costs[26]) and the information trail back to the hospital.

Previous research has relied on statistical analysis or computer simulations to help determine the most effective VF monitoring strategies for patients with glaucoma. This is the first study to use qualitative methods to investigate the patient's own perspective on their follow-up. Studies focusing on the patient's perspective in glaucoma, particularly with regard to the perceived effects of the disease on their day-to-day activities, have typically relied on questionnaires[27]. However, questionnaire responses can be restricted by the wording of the items and provide little opportunity for clarification or elaboration. This study allowed individuals to contextualise their experiences and expand on particular points and themes,

encouraging discussion about topics a certain patient may not have otherwise introduced or attributed to glaucoma without the encouragement of another[11]. The notion of the "expert patient" is beginning to be endorsed with regards to other chronic conditions, with focus groups demonstrating potential as a forum for the development of more effective management strategies[28-30]. Encouraging more patient involvement may also help devise the optimal strategies for glaucoma follow-up.

This study has its limitations with findings attached to the viewpoints of the groups who took part. Efforts were taken to reduce bias by involving multiple research sites but these findings may not necessarily translate to a wider population. It is also important to recognize possible selection bias; the people who chose to participate in a focus group may have more solid opinions with a certain area of their care. Moreover, initial patient selection was made on recommendation of consultants at the clinics and our selection process did not carefully monitor reasons for non-participation. The study was initially designed to involve 6 focus groups across 3 locations and so no direct decision was taken to cease data collection; however, similar themes and sub-themes continued to emerge in the latter focus groups and so it is likely that 'data saturation' was achieved. Also, some biases could have been introduced during interview and analysis due the preconceived ideas held by the experimenters about the areas of importance, although care was taken to adhere to expected practice by following the COREQ check-list for focus group research[13].

A number of important themes did emerge that give an insight into clinic visits and VFs from the patient's perspective, and could help inform patient centred care in glaucoma. Although patients appeared frustrated by a number of aspects of their follow-up, they ultimately accepted that some compromises had to be made in order to save their eyesight. Some of the

viewpoints illustrated in the focus group discussions may in part explain why research-supported guidelines about more frequent VF testing are not being implemented effectively in clinical practice. A holistic approach that embraces patient opinion may therefore be vital to help devise the most effective strategies for follow-up care in this chronic disease.

Conclusion

This is the first study to use qualitative methods to examine patient opinion about the glaucoma clinic experience and VF tests. Although patients found the VF test onerous, they accepted it was important to their overall vision assessment. However, a number of actionable points were raised which were perceived to impact the effectiveness of follow-up care, including distracting testing environments, and hospital constraints relating to excessive waiting times and appointment booking. Some patients also expressed particular concerns about the VF technology used, the quality of test instructions and explanation of results. Anxiety associated with increased testing in the absence of clinical explanation was another theme. Ensuring that glaucoma monitoring is as clinically and cost-effective as possible will inevitably require the confidence and cooperation of the patient. Addressing some or all of the perceived barriers highlighted in this study should help deliver more efficient strategies for VF monitoring in glaucoma.

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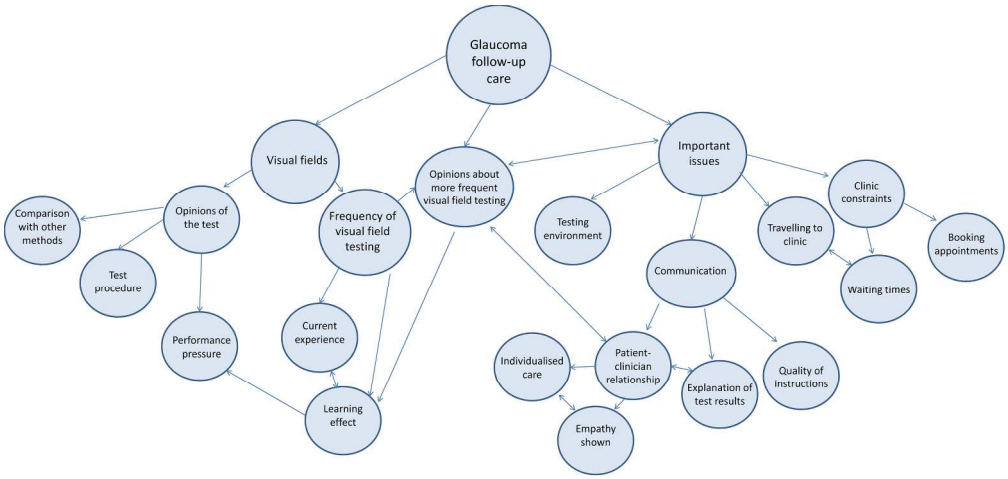

Coding tree showing main themes and sub-themes that emerged from the analysis, and how the categories relate to each other.

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A qualitative investigation into patient views on visual field testing for glaucoma monitoring

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Title: A qualitative investigation into patient views on visual field testing for glaucoma monitoring

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Abstract

Objectives: To investigate the views and experiences of patients regarding their glaucoma follow-up, particularly towards the type and frequency of visual field (VF) testing.

Design: A qualitative investigation using focus groups. The group discussion used broad open questions around the topics in a prompt guide relating to experiences of glaucoma follow-up, and in particular, VF monitoring. All groups were taped, transcribed and coded using manual and computer aided methods.

Setting*:* Three NHS hospitals in England; two focus groups took place at each hospital.

Participants*:* Twenty-eight patients (mean [SD] age: 74 [9] years; 54% female) diagnosed with glaucoma for at least 2 years. Each focus group consisted of 3-6 patients.

Primary and Secondary Outcomes:

1) Attitudes and experiences of patients with glaucoma regarding VF testing

2) Patients' opinions about successful follow-up in glaucoma.

Results: These patients did not enjoy the VF test but they recognised the importance of regular monitoring for preserving their vision. These patients would agree to more frequent VF testing on their clinician's recommendation. A number of themes recurred throughout the focus groups representing perceived barriers to follow-up care. The testing environment, waiting times, efficiency of appointment booking and travel to the clinic were all perceived to influence the general clinical experience and the quality of assessment data. Patients were also

concerned about aspects of patient-doctor communication, and often received little to no feedback about their results.

Conclusions: Patients trust the clinician to make the best decisions for their glaucoma follow-up. However, patients highlighted a number of issues that could compromise the effectiveness of VF testing. Addressing patient-perceived barriers could be an important step for devising optimal strategies for follow-up care.

Article Summary

Article Focus

- Glaucoma is a chronic and progressive eye disease and all diagnosed patients will require lifetime monitoring of their vision.
- Visual field (VF) testing is one of the most widely used assessments for glaucoma and places a large burden on NHS resources; research is needed to devise the most effective strategies for glaucoma VF monitoring.
- This study used focus groups to investigate patient views about VF testing in their follow-up care. Effective VF testing will require the confidence and cooperation of the patient.

Key Messages

- Although patients disliked VF testing, they accepted it as an important part of their vision assessment and disease management.
- Patients discussed a number of areas of perceived importance for VF monitoring, raising particular concerns about distracting testing environments, the quality of test

instructions, how results were explained to them and excessive pre-testing waiting times.

Strengths and Limitations of this study

- This is the first qualitative study to examine patients' views of visual field monitoring using focus groups.
- Focus groups took place at three selected hospitals in the South of England; it is assumed the views expressed represent the experiences of patients in a wider population.
- Not all patients approached by their ophthalmologist took part, but reasons for non-participation were not monitored. Patients who chose to volunteer may be more articulate, motivated and opinionated than the general patient population.

Introduction

Glaucoma is a group of chronic diseases of the optic nerve that, if not managed effectively, could lead to visual impairment or blindness. Currently, the only modifiable risk factor for disease worsening (progression) in glaucoma is reduction of intraocular pressure (IOP). A variety of different approaches to IOP lowering are available, meaning surveillance of the patient is important in selecting the correct intensity of treatment. Over half a million people in the United Kingdom (UK) are thought to have the condition, with patients receiving over a million outpatient visits annually[1 2]. Since the prevalence of glaucoma increases exponentially with age, these figures can be expected to increase dramatically with an ageing population. Glaucoma monitoring therefore represents a major workload for eye services in the National Health Service (NHS).

Assessment of non-seeing or 'blind' areas of the visual field (VF) is central to the monitoring of visual function in glaucoma. The VF is assessed by standard automated perimetry (SAP), a sophisticated automated instrument. The test is carried out in a darkened room and takes about 10 minutes per eye. In short, a patient looks into the part of the instrument that consists of a large semi-circular bowl covering their entire field of view. The instrument presents a series of stimuli (spots of light), one at a time, at a range of contrast levels at varying locations in the VF while the patient fixates on a central point. The patient responds by clicking a button when a stimulus is detected. This process yields a map of the seeing parts of the patient's field of view; this map is subjected to statistical analysis comparing a patient's results to normative values for people with healthy vision. These measurements can be highly variable, and speed (rate) of VF loss, determined from a series of measurements over a period of time, varies considerably between treated individuals. The VF should therefore be monitored at appropriate intervals in order to identify timely intervention of more intensified treatment to

preserve visual function[3]. Yet, evidence regarding how frequently VF tests should be carried out to optimally detect disease progression is limited. The National Institute of Clinical Excellence (NICE) called for more research into examining the effectiveness of using different monitoring intervals to detect disease progression in people with glaucoma in 2009 [1]. Guidelines proposed by the European Glaucoma Society (EGS) recommend that the frequency of VF tests should be increased for newly diagnosed patients in order to better determine speed of VF progression. This notion is supported by research evidence based on statistical analyses of retrospective data which has indicated that three VF tests per year in the first 2 years of follow-up would be clinically useful for identifying patients that are deteriorating at fast rates [4-6]. However, a recent multicentre audit of glaucoma clinics in England indicated that most patients only have about one VF test a year[7]. In another recent study, VF monitoring intervals assigned by clinicians (for hypothetical patient scenarios) were shown to be highly variable[8].

Organisational and resource constraints in the current NHS setting will impact on the feasibility of translating research supported guidelines for VF monitoring to practice. Furthermore, the clinician ultimately drives decision-making based on their own estimates of the likelihood and speed of disease progression, and therefore their opinions towards the appropriateness of monitoring intervals will be important. At the same time, establishing effective monitoring strategies for this chronic condition likely also requires the input of the patients themselves, especially if it equates to more clinic visits. Care plans that place burdens on patients may result in a reduced willingness to return for follow-up and compromise the quality of the data obtained that is subsequently relied on during management[9 10]. Studies have shown that the views of the clinician and the patient regarding aspects of their condition are not always aligned [11 12], implying the patient's perspective must

also be considered. Nevertheless there has been limited use of patient-based research for improving glaucoma care. A review of the literature found that most studies use questionnaires to quickly gather information about the perceptions of patients, usually with regards to their perceived outcomes [13]. However, questionnaires can be impersonal and subject to bias [14 15]. Qualitative techniques, such as focus groups, offer an alternative method of gathering information about not only what a patient thinks, but also how they think or why they may hold a particular view. Group interaction encourages participants to explore and clarify individual and shared perspectives and supports the participation of people who may be reluctant to contribute their views in a more formal one-to-one scenario[16]. Focus groups have been used in a small number of studies to examine the general experiences of glaucoma patients at diagnosis, their expectations and to identify potential barriers to treatment adherence [10 17-19]. However, there is limited evidence regarding the opinions of patients about the manner in which their vision loss is monitored. Anecdotal evidence suggests that patients dislike doing the VF test, and one quantitative study showed that patients rate the VF test least favourably of all the vision assessments [20]. However, no study has interviewed patients with glaucoma in detail about their perceptions of the VF test and their follow-up care. The current study therefore aims to shed light on the effectiveness of glaucoma monitoring from the perspective of the patient by exploring patient views and experiences via focus groups. In particular, the study aims to establish patients' views about VF testing in glaucoma monitoring.

Methods

Participants and methods

Focus groups took place between May 2012 and January 2013 in the following locations: The Queen Alexandra Hospital NHS Trust in Portsmouth; Norfolk and Norwich University Hospital NHS Foundation Trust in Norwich; and Moorfields Eye Hospital NHS Foundation Trust in London. The study was multi-centred to reduce the bias that might come from one geographical area and to encompass healthcare trusts in both urban and rural locations. The sites were chosen because they were involved in a wider programme work, of which the current study was a component. There were two focus groups at each site, with participants allocated to one of the two groups at the corresponding hospital.

The study used purposeful sampling whereby a consultant ophthalmologist at each participating eye hospital selected suitable participants during their routine eye appointment. Specifically, the participant was required to be aged 60 years and over and to be an established glaucoma patient who had been under review for at least two years. These criteria were chosen to reflect the age-related nature of the disease and to ensure that participants had had sufficient experience of VFs as part of their glaucoma follow-up. The ophthalmologist gave potential participants an information sheet, and interested people were asked to sign a form indicating they were happy to be contacted by a researcher (it was stressed that they were not obliged to participate). Each consultant ophthalmologist approached 20 patients in this way. One of the study investigators (HB) then contacted the patients with further information and invited them to take part on one of two specific dates at the corresponding hospital. Those who declined did so because they were not available on the specific dates (no other reason was cited). Initially, 5-6 patients were signed up to participate on each of the six

study dates. However, a small number (n=4) did not attend. A total of 28 participants (mean age [standard deviation] 74 [9] years; 54% female) eventually took part across the six focus groups. Each group consisted of three to six patients and included participants of both genders.

Procedure

A topic guide was devised prior to beginning the study outlining broad question areas regarding general glaucoma care, experiences of the VF test and opinions about VF test frequency. Study topics were informed by an initial pilot exercise involving a discussion with two patients with glaucoma, who also provided additional verbal and written information about their experiences. The topics included in the guide acted only as suggestions; the wording of questions was not predetermined and the order of the topics was not fixed. Prompts were used to introduce topic areas and encourage respondents to elaborate but the onus was on participants to supply the overall content of the discussion. Care was taken to ensure questions were open and "non-leading", although more specific questioning was sometimes used to clarify a point made by a participant. If discussion went substantially off-topic, or one participant was dominating the conversation, the interviewer would reflect back to a previous topic and encourage other participants to contribute their views.

Prior to the study, participants were informed that they would be involved in "an open discussion about (their) experiences in the glaucoma clinic, with special attention to the visual

tests (they) undertake". Participants were not explicitly aware of the emphasis on VF testing, so as to avoid bias linked to the self-selection of participants with strong views on this one topic. All focus groups were conducted by one of the authors (HB), a post-doctoral researcher who had prior experience of qualitative research involving patients with glaucoma [18 21]. The interviewer and participants had no prior knowledge of each other in a clinical or personal context, so each focus group began with general introductions. Field notes were taken during the sessions to aid later interpretation of the data, although note-taking was purposely minimal so that the interviewer could be fully attentive to the discussion. The focus groups lasted between 60 and 75 minutes.

The study received approval from a NHS National Research Ethics Service (NRES) committee and was approved by research governance committees of the participating institutions. The study conformed to the Declaration of Helsinki and written consent from all participants was obtained prior to each focus group.

The study was designed and reported in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) for interviews and focus groups[22].

Analysis

All focus groups were audio-recorded (with permission from the participants). The dialogue from the recordings was later transcribed and reviewed by the investigators. In a small number of instances certain words were inaudible on the recordings due to excessive background noise, so field notes were used to account for any unclear information.

Data was analysed by two of the authors (HB and FCG) independently using framework analysis [23] as displayed in Table 1. Each investigator read and re-read the transcripts and manually identified the key themes from the data in addition to some example quotes to illustrate main points. One of the authors (FCG) was masked to the emphasis on VF testing at this initial point of analysis, although became aware following a subsequent discussion about the key categories that had emerged during that first stage. The qualitative software package NVIVO 10.2 (QSR International, Cambridge, Massachusetts) was used to organise the thematic framework by refining and condensing the categories that had been manually identified and to identify additional themes for exploration. Any differences of opinion regarding the meaning of sentences or the importance of themes were discussed until a consensus was reached.

Table 1: Framework Technique used for data analysis

Framework Technique		
1.	Familiarisation	Reading and re-reading the transcriptions
2.	Identifying a Thematic Framework	Condense data into categories
3.	Indexing	Codes systematically applied to the data
4.	Charting	Re-arranging the data according to the thematic content in a way which allows for a cross case and within case analysis
5.	Mapping and Interpretation	Interpretations and recommendations

Findings

Data was initially indexed according to themes central to the main research questions, such as opinions of the VF test, current experience regarding the frequency of VF testing and opinions about more frequent VF testing. Throughout the analysis a number of additional themes emerged, often with their own sub-themes; these generally related to specific areas perceived to affect the follow-up experience, and included points relating to clinical constraints (waiting times, booking appointments), travel to the clinic, the testing environment and aspects of patient-clinician communication. The themes and sub-themes are summarised in Figure 1.

Figure 1: Coding tree showing main themes and sub-themes that emerged from the analysis, and how the categories relate to each other.

Direct quotes taken from the transcripts are italicized. These quotes were examples chosen to illustrate the key themes that emerged from the focus groups. Excerpts are annotated with a pseudonym for the corresponding participant based on their gender ("M" or "F") and the order in which they spoke in the interview. The location of the focus group and the session number (1 or 2) are also shown for each quote.

Visual fields – Opinions about testing

Visual fields - Test procedure

Patients expressed a dislike for the VF test. They found the test time-consuming, old-fashioned and tiring.

Well the reason why I don't like them: I don't like the dark, I don't like confined spaces and I don't like having one eye closed and having to concentrate, even if it's for just a couple of minutes, because then my mind wanders… F1, Portsmouth 1

It seems a bit antiquated, pressing the buttons… it doesn't seem positive enough to me. F3 Norwich 2

I appreciate the need for it…but it's so time consuming M2 London 1

Visual fields - Performance pressure

Many put pressure on themselves to perform the test well, as they felt there could be a lot riding on their performance.

There is pressure: I think it is because your eyes are so important for everyday living, that, you know, you're frightened to [not do well]. F2 Portsmouth 1

There was a general appreciation that such testing was vital to preserve their vision.

Well… obviously I'm very grateful that I'm being monitored all… F4 London 1

....mine has been 10 years and you think, well how long will I have my sight? ... My mum had lost her sight by then, you know... F3 Norwich 2

Visuals fields - Comparison with other tests

Patients found other tests used in their clinical monitoring, such as visual acuity, intraocular pressure measurement and imaging tests, less tiring and laborious. At the same time some patients felt the VF test was more 'valuable', providing more reassurance that their condition was being investigated.

[with] the [imaging] there's just one person, one machine and you, and it's done and that's it, it's over...within minutes. F3 Norwich 2

... they look in your eyes to measure your pressure but when you do that field test, they see more.... F1 London 2

Frequency of visual field testing – Current experience

VF tests were usually performed once or twice a year, either during or closely prior to the patient's general clinical appointment. Patients who visited the clinic more frequently would have a VF test at only some of their appointments. Some patients were often unaware as to whether they would have a VF test during their visit.

I mean they just say you're going to come for your next appointment in whatsoever, whatever time, but they don't say, 'Oh, in that time you will be having a visual field check', so that you know that you are going to have to be that little bit longer.. F2 Portsmouth 1

Frequency of visual field testing – Opinions about more testing

When patients were asked whether they would be willing to visit the clinic for VF testing more frequently, there was a reluctant agreement. The test was viewed as a '*necessary evil*' and most were open to more frequent testing if the clinician felt it would enhance their prognosis, although there was scepticism as to how useful the test actually was.

If it was necessary. F2 Portsmouth 2

You'd get on with it. M1 Portsmouth 2

If it helps the cause so be it. M2 Portsmouth 2

I don't want to lose my sight, I'd come in whenever. F2 Portsmouth 2

If it holds it back for 10 years… I'm happy with another 10 years! M1 Norwich 2

That's a problem with glaucoma, you can't leave it for too long
M2 London 2

… I suppose I'd accept it because I would hope that the reason for asking me was that they will get more information from that, which obviously deals with the whole problem but…I'm not really sure at all about how useful they are. I mean is it just statistics or whatever? …I'm sure they're useful but I wonder in what proportion of use they are compared to, you know, looking in the eye and pressures and things….

F3 Norwich 2

Some patients associated more frequent testing with worsening vision; therefore being asked to attend for more testing could lead to increased anxiety.

... you'd think they've called me back 'cause it's going, deteriorating. But I mean if they said to do it, I've always done ... because they're doing the best for me…

F3 Norwich 2

Frequency of visual field testing - Learning effect

One recurrent topic regarding VF testing was issues relating to the learning effect, whereby performance improves with increased testing. Some suggested that more repeat testing would be helpful. However, the repeated tests may only be worthwhile if they took place at the beginning of their follow-up care.

...interestingly I went and did one once and they said to me, "this has improved from the last time" and I said "well I think I'm just getting better at computer games" ... I think you do know what's coming and you can improve and I just feel more comfortable with doing it.

F1 Norwich 1

I think to do a field test right at the beginning, and to take that as being the definitive field test is wrong…because I think you need to do a test and think, and revise it in your mind what you've done and then do it again. M1 Portsmouth 2

There was some debate about the period of time between VF tests.

I think you need to do a field test and then perhaps a month later do the second one.

M1 Portsmouth 2

Well not if you have a long gap between them. F1 Norwich 2

I've got used to it now. F2 Norwich 2

I don't think it's any different really. F3 Norwich 2

Perceived issues and barriers for successful follow-up care

Some additional themes emerged during the analysis, highlighting a number of areas perceived to be important and potentially representing barriers to successful follow-up.

Communication - Visual field instructions

Regardless of how long they had been attending the glaucoma clinic, patients appreciated having the VF test procedure fully explained to them. It was rare for a staff member to stay with the patient throughout the test, but on the occasions it did happen, patients found the experience reassuring and felt the encouragement helped their performance.

... They say, "Have you done this before?" You say "Yes". And that's it, you're left there and eventually they say, "Have you finished?

M1 Portsmouth 2

I had one about three weeks ago and it was a young nurse and it was a completely different experience. She was professional, polite, kind; she told me exactly what they were doing.... it was almost a pleasant experience. F1 Portsmouth 1

There was discussion about understanding aspects of the testing procedure and how the procedure was explained. For example, some patients expressed uncertainty and felt test pressure would influence their results. Again, explanation and reassurance before and after the test helped.

The staff told me: "don't worry about missing [a light] because it'll come later", so you know you get a second chance. F1 Norwich 1

... if in doubt press the button, don't you? F1 Portsmouth 2

Communication - Explanation of results

Most patients said they had to specifically enquire about their results to find out information about their vision and whether their condition had progressed since the last appointment. Some patients felt intimidated to ask the clinician for feedback as to how they had performed, feeling they were being a nuisance or wasting the clinician's time.

They never discuss the result of the field test unless I ask…

M2 London 2

My wife always says "how did you get on?" and I say "I don't know", and that's one of the problems. M2 Portsmouth 2

I don't think they've got time to listen to you, or they don't appear to, and I don't know whether they would listen…. You feel pathetic asking these questions. F3 Portsmouth 1

Patients may be more inclined to have VF tests more frequently should they be informed clearly about what the results indicate about their prognosis.

I don't mind how many times I do it providing I get a result of the test at that time compared to what the previous one was. Is there any improvement? Is there any downgrade? M1 Portsmouth 1

Communication - The patient-clinician relationship

The quality of relationship with the clinical staff and aspects of patient-clinician communication also emerged as key factors influencing perceptions of the follow-up process.

An apparent lack of personalised care caused unease: there was a sentiment that sometimes the clinician simply looked at the eyes and failed to consider the person's individual needs.

You're not a person, you know, you've just got eyes, they're just going to deal with that and that's it. F3 Portsmouth 1

The experience was seen to be much more bearable if they felt the staff member dealing with them was empathic.

Even buying a chop, you know: if the butcher's interested, it helps doesn't it?

M3 Norwich 1

The opportunity to spend more time with their consultant ophthalmologist was a key factor that influenced whether or not patients were open to visiting the clinic more frequently.

Not [just] for the field test... But I wouldn't mind coming in more to see the doctor.

M2 London 2

Testing environment

The testing environment was another important theme. The dark room, especially if it was warm, made focusing on the tests difficult. Patients felt they performed better in the morning when they were more alert. Ambient noise in the room made it difficult to concentrate; staff members talking and doing the test at the same time as several other patients all had deleterious effects.

I will also say that the staff chatter a lot, which is difficult for concentration; the doors open and close, there's a lot of noise. F1 Norwich 1

I find it difficult sometimes when people [move] about behind you…

M1 London 1

The times that I've had the visual field test done in a room where there's just one [machine], I felt more confident to do it; it was much quieter and more relaxed and it seemed to be a lot quicker too. F3 Norwich 2

I think having the quieter atmosphere would generally help I'm sure….just that feeling of slight calm, you can relax more and then it probably would be a lot quicker because maybe you're not going to miss as many [lights] as you haven't got other distractions. F3 Norwich 2.

The idea was raised that routine VF testing could be carried out in a more convenient location. Some patients had previously visited a local optometrist to carry out a VF test for the purpose of assessing their legal fitness to drive. On the positive side, patients liked the convenience of doing so and described a better testing environment. Conversely, they questioned the competency of the staff, the quality of the equipment and the information trail back to the hospital.

The principle of having routine tests done locally is acceptable providing they are trained.

M1 London 1

That way you would be there, dealt with by people you know probably more intimately…you're in a more relaxed environment…

M1 Norwich 1

I would be concerned about how often the machine was calibrated to get an accurate reading.

M2 London 1

Is the information going back to where it matters in my notes? Things do get lost, and will someone actually look at the test?

M1 London 2

Some felt they had built up a level of trust with the hospital eye service and would therefore prefer to have VFs conducted in this environment.

I've been here for quite a while now and I like coming to them: I don't want to go anywhere else. F1 London 2

I would feel the same because it's a matter of trust. M2 London 2

Clinic constraints -Waiting times

Waiting times were a major concern at all locations. The standard time taken per visit was estimated to be two hours, although the wait was often unpredictable. Established patients were used to the wait and tried not to let it affect them but they still found the system frustrating. Patients were scared of missing their slots and, therefore, would not leave their seat in the waiting area.

No way I'm going to nip off ... especially as now I'm on my own, no way…. just even nipping off to the [bathroom] because you think, 'He's bound to call me. I can sit here for an hour and he'll call me the minute I go to the [bathroom]. F2 Portsmouth 1

Although it was repeatedly acknowledged that the clinics were very busy, which had the knock-on effect of increased waiting times, patients felt they were getting adequate treatment overall. It was suggested that there was a trade-off between longer waiting times and higher quality treatment:

I think that's a very fair price to pay for the fact that you're being dealt with in a UK centre of excellence. There's a trade-off in that you're getting state of the art treatment but the price is you've got to sit around for it. M1 London 1

Clinic constraints - Travelling to the clinic

Several sub-themes emerged including issues with long distances to travel, avoiding rush hours, travel costs and travelling alone.

I think the problem is because I live nearly an hour away, for me the nearest hospital is an hour away… F2 Norwich 2

Taxi is the only way I can do it now. You know, I can get to the station by bus and possibly with help to get on the train but it's not easy…..It's horrific, frightening. M2 London 1

Tiring journeys to the clinic and late clinic appointments were also sometimes perceived to have a negative effect on VF test performance.

I think if you did the eye check later in the day, you know, if your eyes were tired, it might make you feel [that you] wouldn't see so well... F2 Portsmouth 1

Clinic constraints - Scheduling appointments

The scheduling of appointments was a major concern: often the systems were so overbooked that patients were unable to make their next appointment at their clinic visit.

You can only make an appointment six weeks in advance. You used to get a twelve month appointment letter just after you had been for an appointment; now its six weeks before you are due. M2 Norwich 1

Often patients would receive an appointment only to have it cancelled just before the clinic was due to take place. This was not only frustrating to people who had made arrangements for their appointment, such as asking a friend to accompany them or arranging cover for sick spouses, it caused concern that their appointment was to be at a much later date than the clinician had originally requested.

"So if you've been given a six month appointment and it's cancelled, and you're not given another one, you ring up and then they say "oh we can't give you an appointment now until October". That was 10 months. Now if your consultant says 6 [months] and it's 10 and something's gone wrong with your vision in between, you have no way of telling." F2 Portsmouth 2

Patient recommendations

At the end of the focus groups, patients were asked to recommend changes to improve their follow-up care. The recommendations were similar across all locations and the most popular suggestions are displayed in table 2.

Table 2: Patient recommendations for improving follow-up care.

Patient Recommendations	
1.	Less waiting and clinics running to time.
2.	Flexible booking and changing of appointments.
3.	To have a calmer, quieter environment in the visual field room with less people doing the test at the same time.
4.	To modernise the visual field test.
5.	To have more continuity of care by seeing the same clinician at each visit.
6.	To receive better communication from the clinician.

Discussion

Data from this study supports evidence from elsewhere that patients find VF testing more laborious and demanding than other vision tests[20]. Nevertheless, patients were willing to complete more VF tests on the guidance of their clinician, as ultimately they were prepared to do whatever it took to preserve their vision. Thus, patients may tolerate more frequent VF testing during the first two years of their follow-up care as recommended by the research literature[4 5] and some clinical guidelines[24] . Patients commented that it took time to feel comfortable with the test procedure, and that multiple attempts were needed to gain an accurate representation of their vision. These viewpoints complement existing evidence showing that performance can improve considerably during follow-up due to gaining experience with the testing process[25].

There were, however, a number of additional themes that emerged from the data which identified areas that could represent potential barriers to successful glaucoma monitoring. Patients felt that the environment in which they completed the VF test was linked to how well they were able to perform the task, with staff members talking loudly, the number of people in the room, and the time of day all listed as important interfering factors. These views coincide with other evidence showing that the environment, the technician and the time of day do have a significant influence on measurement variability from VF tests[26]. Fatigue, a topic mentioned frequently throughout the discussions, has also been shown to affect performance as test duration increases[27].

Patients highlighted the importance of effective task communication for influencing their VF test performance. Prior evidence has shown that the quality of instruction given before the VF test can significantly affect subsequent estimations of VF defect severity[28 29]. Patients also felt

that it was essential to have the task explained to them properly, even if they had been attending clinics for some time. Having a staff member in the room whilst they carried out the test was found to be reassuring. These findings reiterate the idea that ensuring that the task demands are communicated clearly and effectively before every VF test, and being on hand to alleviate any concerns or questions that the patient may have, may help maximise the quality of the data gained from the assessment[29-31].

Other discussion points relating to communication were also raised repeatedly throughout the focus groups. Patients felt that many clinicians treated them as an 'eye' rather than a person, with those staff members who took a more individualistic and empathic approach viewed favourably. Notably, patients felt that they had to ask explicitly about their results in order to learn details about their own condition. Evidence has shown that that the patient and clinician's views of their condition are not always aligned, which may be due to miscommunication or misinterpretation of key information on both parts[32]. By explaining the results in a clear, simple and concise manner, the patient will inevitably improve their understanding of their condition, which in turn could influence how well they respond to important aspects of their follow-up care. For instance, it has been shown that the way in which clinicians communicate with the patient can influence future adherence to medication[32]. It has been suggested that clinicians underestimate the importance of effective communication to the patient [11], and in one study examining patient expectations for eye care, the emphasised areas were all related to communication and interpersonal manner [33]. Providing better information about the purpose of VF testing, what is required of the patient, and their results and general prognosis could be vital for improving attendance for VF tests or for the subsequent quality of data obtained. Perhaps developers of SAP ought to think about ways in which the complex measurement of the VF could be easily presented and

communicated to patients. It is important to note that some patients associated more frequent testing with worsening vision, which caused some distress. Thus, should patients require more frequent tests at some point in their care, it is also vital to involve the patient and explain reasons for the decision.

Excessive waiting times and difficultly booking appointments were also major concerns. In particular, patients worried that appointment cancellations could extend the interval between tests beyond what was recommended by the clinician, therefore leaving them exposed to undetected disease progression. It is known that whilst clinicians select appropriate monitoring intervals, hospital-initiated rescheduling is a major challenge to appropriate follow-up[7 34 35]. Moreover, it was typical for patients to wait at the clinic for hours in order to complete multiple vision tests, causing frustration and tiredness which some perceived to influence their subsequent performance. Potential solutions could involve conducting only the VF test during short independent appointment slots, or carrying out tests at a more convenient location. However, such strategies would involve further investigation as to their overall cost-effectiveness and should address other associated practicalities such as travel (a significant contributor to total patient costs[36]) and the information trail back to the hospital.

Previous research has relied on statistical analysis or computer simulations to help determine the most effective VF monitoring strategies for patients with glaucoma. This is the first study to use qualitative methods to investigate the patient's own perspective on their follow-up. Studies focusing on the patient's perspective in glaucoma, particularly with regard to the perceived effects of the disease on their day-to-day activities, have typically relied on questionnaires [13]. However, questionnaire responses can be restricted by the wording of the items and provide little opportunity for clarification or elaboration. This study allowed

individuals to contextualise their experiences and expand on particular points and themes, encouraging discussion about topics a certain patient may not have otherwise introduced or attributed to glaucoma without the encouragement of another[18]. The notion of the "expert patient" is beginning to be endorsed with regards to other chronic conditions, with focus groups demonstrating potential as a forum for the development of more effective management strategies[37-39]. Furthermore, patient groups have aided the development of health education programmes for age-related macular degeneration[40]. A systematic review of patient centred randomised controlled trials suggests there may be some benefits associated with involving patients with chronic disease in programmes geared towards better educating service users and devising general training for health professionals[41]. Future work that encourages more patient involvement may therefore help devise the optimal strategies for glaucoma follow-up and also help better inform both patients and health professionals about the condition.

This study has its limitations with findings attached to the viewpoints of the groups who took part. Efforts were taken to reduce bias by involving multiple research sites- however, these were all geographically limited to the South of England and (excluding the London groups) involved patients of Caucasian ethnicity. Therefore the findings may not necessarily translate to a wider population. Moreover, initial patient selection was made on recommendation of consultants at the clinics and our selection process did not monitor reasons for non-participation. People who choose to volunteer for focus groups are likely to be articulate and confident; they may also be more motivated to take part due to having more severe disease or holding strong opinions about a certain area of their care. Furthermore, participants were aged 60 years and older- younger service-users may have differing views and experiences that also warrant investigation. The study was initially designed to involve 6 focus groups across 3 locations and so no direct decision was taken to cease data collection; however, similar

themes and sub-themes continued to emerge in the latter focus groups and so it is likely that 'data saturation' was achieved. Furthermore, some of the focus groups were small (one consisting of only 3 participants) due to late cancellations but this is not a major limitation due to the number of focus groups that took place [42]. Also, some biases could have been introduced during interview and analysis due the preconceived ideas held by the experimenters about the areas of importance, although care was taken to adhere to expected practice by following the COREQ check-list for focus group research[22].

A number of important themes did emerge that give an insight into clinic visits and VFs from the patient's perspective, and could help inform patient centred care in glaucoma. Although patients appeared frustrated by a number of aspects of their follow-up, they ultimately accepted that some compromises had to be made in order to save their eyesight. Some of the viewpoints illustrated in the focus group discussions may in part explain why research-supported guidelines about more frequent VF testing are not being implemented effectively in clinical practice. A holistic approach that embraces patient opinion may therefore be vital to help devise the most effective strategies for follow-up care in this chronic disease.

Conclusion

This is the first study to use qualitative methods to examine patient opinion about the glaucoma clinic experience and VF tests. Although patients found the VF test onerous, they accepted it was important to their overall vision assessment. However, a number of actionable points were raised which were perceived to impact the effectiveness of follow-up care, including distracting testing environments, and hospital constraints relating to excessive waiting times and appointment booking. Some patients also expressed particular concerns

about the VF technology used and the quality of test instructions. Anxiety associated with increased testing in the absence of clinical explanation was another theme. Ensuring that glaucoma monitoring is as clinically and cost-effective as possible will inevitably require the confidence and cooperation of the patient. Addressing some or all of the perceived barriers highlighted in this study should help deliver more efficient strategies for VF monitoring in glaucoma.

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Contributions of authors

FCG: Conducted data analysis, and wrote and edited the manuscript (joint first author).

HB: Conducted focus groups and data analysis, and wrote the manuscript (joint first author).

DPC: Conceived and designed study, and reviewed and edited the manuscript.

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Competing Interest Statement

None of the authors have any competing interests in relation to this work.

Data Sharing Statement

Copies of the topic guide and participant information sheet can be obtained by emailing the corresponding author.

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Title: A qualitative investigation into patient views on visual field testing for glaucoma monitoring

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Contributions of authors

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HB: Conducted focus groups and data analysis, and wrote the manuscript (joint first author).

DPC: Conceived and designed study, and reviewed and edited the manuscript.

Abstract

Objectives: To investigate the views and experiences of patients regarding their glaucoma follow-up, particularly towards the type and frequency of visual field (VF) testing.

Design: A qualitative investigation using focus groups. The group discussion used broad open questions around the topics in a prompt guide relating to experiences of glaucoma follow-up, and in particular, VF monitoring. All groups were taped, transcribed and coded using manual and computer aided methods.

Setting*:* Three NHS hospitals in England; two focus groups took place at each hospital.

Participants*:* Twenty-eight patients (mean [SD] age: 74 [9] years; 54% female) diagnosed with glaucoma for at least 2 years. Each focus group consisted of 3-6 patients.

Primary and Secondary Outcomes:

1) Attitudes and experiences of patients with glaucoma regarding VF testing

2) Patients' opinions about successful follow-up in glaucoma.

Results: These patients did not enjoy the VF test but they recognised the importance of regular monitoring for preserving their vision. These patients would agree to more frequent VF testing on their clinician's recommendation. A number of themes recurred throughout the focus groups representing perceived barriers to follow-up care. The testing environment, waiting times, efficiency of appointment booking and travel to the clinic were all perceived to influence the general clinical experience and the quality of assessment data. Patients were also

concerned about aspects of patient-doctor communication, and often received little to no feedback about their results.

Conclusions: Patients trust the clinician to make the best decisions for their glaucoma follow-up. However, patients highlighted a number of issues that could compromise the effectiveness of VF testing. Addressing patient-perceived barriers could be an important step for devising optimal strategies for follow-up care.

Article Summary

Article Focus

- Glaucoma is a chronic and progressive eye disease and all diagnosed patients will require lifetime monitoring of their vision.
- Visual field (VF) testing is one of the most widely used assessments for glaucoma and places a large burden on NHS resources; research is needed to devise the most effective strategies for glaucoma VF monitoring.
- This study used focus groups to investigate patient views about VF testing in their follow-up care. Effective VF testing will require the confidence and cooperation of the patient.

Key Messages

- Although patients disliked VF testing, they accepted it as an important part of their vision assessment and disease management.
- Patients discussed a number of areas of perceived importance for VF monitoring, raising particular concerns about distracting testing environments, the quality of test

instructions, how results were explained to them and excessive pre-testing waiting times.

Strengths and Limitations of this study

- This is the first qualitative study to examine patients' views of visual field monitoring using focus groups.
- Focus groups took place at three selected hospitals in the South of England; it is assumed the views expressed represent the experiences of patients in a wider population.
- Not all patients approached by their ophthalmologist took part, but reasons for non-participation were not monitored. Patients who chose to volunteer may be more articulate, motivated and opinionated than the general patient population.

Introduction

Glaucoma is a group of chronic diseases of the optic nerve that, if not managed effectively, could lead to visual impairment or blindness. Currently, the only modifiable risk factor for disease worsening (progression) in glaucoma is reduction of intraocular pressure (IOP). A variety of different approaches to IOP lowering are available, meaning surveillance of the patient is important in selecting the correct intensity of treatment. Over half a million people in the United Kingdom (UK) are thought to have the condition, with patients receiving over a million outpatient visits annually[1 2]. Since the prevalence of glaucoma increases exponentially with age, these figures can be expected to increase dramatically with an ageing population. Glaucoma monitoring therefore represents a major workload for eye services in the National Health Service (NHS).

Assessment of non-seeing or 'blind' areas of the visual field (VF) is central to the monitoring of visual function in glaucoma. The VF is assessed by standard automated perimetry (SAP), a sophisticated automated instrument. The test is carried out in a darkened room and takes about 10 minutes per eye. In short, a patient looks into the part of the instrument that consists of a large semi-circular bowl covering their entire field of view. The instrument presents a series of stimuli (spots of light), one at a time, at a range of contrast levels at varying locations in the VF while the patient fixates on a central point. The patient responds by clicking a button when a stimulus is detected. This process yields a map of the seeing parts of the patient's field of view; this map is subjected to statistical analysis comparing a patient's results to normative values for people with healthy vision. These measurements can be highly variable, and speed (rate) of VF loss, determined from a series of measurements over a period of time, varies considerably between treated individuals. The VF should therefore be monitored at appropriate intervals in order to identify timely intervention of more intensified treatment to

preserve visual function[3]. Yet, evidence regarding how frequently VF tests should be carried out to optimally detect disease progression is limited. The National Institute of Clinical Excellence (NICE) called for more research into examining the effectiveness of using different monitoring intervals to detect disease progression in people with glaucoma in 2009 [1]. Guidelines proposed by the European Glaucoma Society (EGS) recommend that the frequency of VF tests should be increased for newly diagnosed patients in order to better determine speed of VF progression. This notion is supported by research evidence based on statistical analyses of retrospective data which has indicated that three VF tests per year in the first 2 years of follow-up would be clinically useful for identifying patients that are deteriorating at fast rates [4-6]. However, a recent multicentre audit of glaucoma clinics in England indicated that most patients only have about one VF test a year[7]. In another recent study, VF monitoring intervals assigned by clinicians (for hypothetical patient scenarios) were shown to be highly variable[8].

Organisational and resource constraints in the current NHS setting will impact on the feasibility of translating research supported guidelines for VF monitoring to practice. Furthermore, the clinician ultimately drives decision-making based on their own estimates of the likelihood and speed of disease progression, and therefore their opinions towards the appropriateness of monitoring intervals will be important. At the same time, establishing effective monitoring strategies for this chronic condition likely also requires the input of the patients themselves, especially if it equates to more clinic visits. Care plans that place burdens on patients may result in a reduced willingness to return for follow-up and compromise the quality of the data obtained that is subsequently relied on during management[9 10]. Studies have shown that the views of the clinician and the patient regarding aspects of their condition are not always aligned [11 12], implying the patient's perspective must

also be considered. Nevertheless there has been limited use of patient-based research for improving glaucoma care. A review of the literature found that most studies use questionnaires to quickly gather information about the perceptions of patients, usually with regards to their perceived outcomes [13]. However, questionnaires can be impersonal and subject to bias [14 15]. Qualitative techniques, such as focus groups, offer an alternative method of gathering information about not only what a patient thinks, but also how they think or why they may hold a particular view. Group interaction encourages participants to explore and clarify individual and shared perspectives and supports the participation of people who may be reluctant to contribute their views in a more formal one-to-one scenario[16]. Focus groups have been used in a small number of studies to examine the general experiences of glaucoma patients at diagnosis, their expectations and to identify potential barriers to treatment adherence [10 17-19]. However, there is limited evidence regarding the opinions of patients about the manner in which their vision loss is monitored. Anecdotal evidence suggests that patients dislike doing the VF test, and one quantitative study showed that patients rate the VF test least favourably of all the vision assessments [20]. However, no study has interviewed patients with glaucoma in detail about their perceptions of the VF test and their follow-up care. The current study therefore aims to shed light on the effectiveness of glaucoma monitoring from the perspective of the patient by exploring patient views and experiences via focus groups. In particular, the study aims to establish patients' views about VF testing in glaucoma monitoring.

Methods

Participants and methods

Focus groups took place between May 2012 and January 2013 in the following locations: The Queen Alexandra Hospital NHS Trust in Portsmouth; Norfolk and Norwich University Hospital NHS Foundation Trust in Norwich; and Moorfields Eye Hospital NHS Foundation Trust in London. The study was multi-centred to reduce the bias that might come from one geographical area and to encompass healthcare trusts in both urban and rural locations. The sites were chosen because they were involved in a wider programme work, of which the current study was a component. There were two focus groups at each site, with participants allocated to one of the two groups at the corresponding hospital.

The study used purposeful sampling whereby a consultant ophthalmologist at each participating eye hospital selected suitable participants during their routine eye appointment. Specifically, the participant was required to be aged 60 years and over and to be an established glaucoma patient who had been under review for at least two years. These criteria were chosen to reflect the age-related nature of the disease and to ensure that participants had had sufficient experience of VFs as part of their glaucoma follow-up. The ophthalmologist gave potential participants an information sheet, and interested people were asked to sign a form indicating they were happy to be contacted by a researcher (it was stressed that they were not obliged to participate). Each consultant ophthalmologist approached 20 patients in this way. One of the study investigators (HB) then contacted the patients with further information and invited them to take part on one of two specific dates at the corresponding hospital. Those who declined did so because they were not available on the specific dates (no other reason was cited). Initially, 5-6 patients were signed up to participate on each of the six

study dates. However, a small number (n=4) did not attend. A total of 28 participants (mean age [standard deviation] 74 [9] years; 54% female) eventually took part across the six focus groups. Each group consisted of three to six patients and included participants of both genders.

Procedure

A topic guide was devised prior to beginning the study outlining broad question areas regarding general glaucoma care, experiences of the VF test and opinions about VF test frequency. Study topics were informed by an initial pilot exercise involving a discussion with two patients with glaucoma, who also provided additional verbal and written information about their experiences. The topics included in the guide acted only as suggestions; the wording of questions was not predetermined and the order of the topics was not fixed. Prompts were used to introduce topic areas and encourage respondents to elaborate but the onus was on participants to supply the overall content of the discussion. Care was taken to ensure questions were open and "non-leading", although more specific questioning was sometimes used to clarify a point made by a participant. If discussion went substantially off-topic, or one participant was dominating the conversation, the interviewer would reflect back to a previous topic and encourage other participants to contribute their views.

Prior to the study, participants were informed that they would be involved in "an open discussion about (their) experiences in the glaucoma clinic, with special attention to the visual

tests (they) undertake". Participants were not explicitly aware of the emphasis on VF testing, so as to avoid bias linked to the self-selection of participants with strong views on this one topic. All focus groups were conducted by one of the authors (HB), a post-doctoral researcher who had prior experience of qualitative research involving patients with glaucoma [18 21]. The interviewer and participants had no prior knowledge of each other in a clinical or personal context, so each focus group began with general introductions. Field notes were taken during the sessions to aid later interpretation of the data, although note-taking was purposely minimal so that the interviewer could be fully attentive to the discussion. The focus groups lasted between 60 and 75 minutes.

The study received approval from a NHS National Research Ethics Service (NRES) committee and was approved by research governance committees of the participating institutions. The study conformed to the Declaration of Helsinki and written consent from all participants was obtained prior to each focus group.

The study was designed and reported in accordance with the Consolidated Criteria for Reporting Qualitative Research (COREQ) for interviews and focus groups[22].

Analysis

All focus groups were audio-recorded (with permission from the participants). The dialogue from the recordings was later transcribed and reviewed by the investigators. In a small number of instances certain words were inaudible on the recordings due to excessive background noise, so field notes were used to account for any unclear information.

Data was analysed by two of the authors (HB and FCG) independently using framework analysis [23] as displayed in Table 1. Each investigator read and re-read the transcripts and manually identified the key themes from the data in addition to some example quotes to illustrate main points. One of the authors (FCG) was masked to the emphasis on VF testing at this initial point of analysis, although became aware following a subsequent discussion about the key categories that had emerged during that first stage. The qualitative software package NVIVO 10.2 (QSR International, Cambridge, Massachusetts) was used to organise the thematic framework by refining and condensing the categories that had been manually identified and to identify additional themes for exploration. Any differences of opinion regarding the meaning of sentences or the importance of themes were discussed until a consensus was reached.

Table 1: Framework Technique used for data analysis

Framework Technique		
1.	Familiarisation	Reading and re-reading the transcriptions
2.	Identifying a Thematic Framework	Condense data into categories
3.	Indexing	Codes systematically applied to the data
4.	Charting	Re-arranging the data according to the thematic content in a way which allows for a cross case and within case analysis
5.	Mapping and Interpretation	Interpretations and recommendations

Findings

Data was initially indexed according to themes central to the main research questions, such as opinions of the VF test, current experience regarding the frequency of VF testing and opinions about more frequent VF testing. Throughout the analysis a number of additional themes emerged, often with their own sub-themes; these generally related to specific areas perceived to affect the follow-up experience, and included points relating to clinical constraints (waiting times, booking appointments), travel to the clinic, the testing environment and aspects of patient-clinician communication. The themes and sub-themes are summarised in Figure 1.

Figure 1: Coding tree showing main themes and sub-themes that emerged from the analysis, and how the categories relate to each other.

Direct quotes taken from the transcripts are italicized. These quotes were examples chosen to illustrate the key themes that emerged from the focus groups. Excerpts are annotated with a pseudonym for the corresponding participant based on their gender ("M" or "F") and the order in which they spoke in the interview. The location of the focus group and the session number (1 or 2) are also shown for each quote.

Visual fields – Opinions about testing

Visual fields - Test procedure

Patients expressed a dislike for the VF test. They found the test time-consuming, old-fashioned and tiring.

Well the reason why I don't like them: I don't like the dark, I don't like confined spaces and I don't like having one eye closed and having to concentrate, even if it's for just a couple of minutes, because then my mind wanders… F1, Portsmouth 1

It seems a bit antiquated, pressing the buttons… it doesn't seem positive enough to me. F3 Norwich 2

I appreciate the need for it…but it's so time consuming M2 London 1

Visual fields - Performance pressure

Many put pressure on themselves to perform the test well, as they felt there could be a lot riding on their performance.

There is pressure: I think it is because your eyes are so important for everyday living, that, you know, you're frightened to [not do well]. F2 Portsmouth 1

There was a general appreciation that such testing was vital to preserve their vision.

Well… obviously I'm very grateful that I'm being monitored all… F4 London 1

….mine has been 10 years and you think, well how long will I have my sight? … My mum had lost her sight by then, you know… F3 Norwich 2

Visuals fields - Comparison with other tests

Patients found other tests used in their clinical monitoring, such as visual acuity, intraocular pressure measurement and imaging tests, less tiring and laborious. At the same time some patients felt the VF test was more 'valuable', providing more reassurance that their condition was being investigated.

[with] the [imaging] there's just one person, one machine and you, and it's done and that's it, it's over…within minutes. F3 Norwich 2

… they look in your eyes to measure your pressure but when you do that field test, they see more…. F1 London 2

Frequency of visual field testing – Current experience

VF tests were usually performed once or twice a year, either during or closely prior to the patient's general clinical appointment. Patients who visited the clinic more frequently would have a VF test at only some of their appointments. Some patients were often unaware as to whether they would have a VF test during their visit.

I mean they just say you're going to come for your next appointment in whatsoever, whatever time, but they don't say, 'Oh, in that time you will be having a visual field check', so that you know that you are going to have to be that little bit longer.. F2 Portsmouth 1

Frequency of visual field testing – Opinions about more testing

When patients were asked whether they would be willing to visit the clinic for VF testing more frequently, there was a reluctant agreement. The test was viewed as a '*necessary evil*' and most were open to more frequent testing if the clinician felt it would enhance their prognosis, although there was scepticism as to how useful the test actually was.

If it was necessary. F2 Portsmouth 2

You'd get on with it. M1 Portsmouth 2

If it helps the cause so be it. M2 Portsmouth 2

I don't want to lose my sight, I'd come in whenever. F2 Portsmouth 2

If it holds it back for 10 years… I'm happy with another 10 years! M1 Norwich 2

That's a problem with glaucoma, you can't leave it for too long
M2 London 2

… I suppose I'd accept it because I would hope that the reason for asking me was that they will get more information from that, which obviously deals with the whole problem but…I'm not really sure at all about how useful they are. I mean is it just statistics or whatever? …I'm sure they're useful but I wonder in what proportion of use they are compared to, you know, looking in the eye and pressures and things….

F3 Norwich 2

Some patients associated more frequent testing with worsening vision; therefore being asked to attend for more testing could lead to increased anxiety.

... you'd think they've called me back 'cause it's going, deteriorating. But I mean if they said to do it, I've always done ... because they're doing the best for me…

F3 Norwich 2

Frequency of visual field testing - Learning effect

One recurrent topic regarding VF testing was issues relating to the learning effect, whereby performance improves with increased testing. Some suggested that more repeat testing would be helpful. However, the repeated tests may only be worthwhile if they took place at the beginning of their follow-up care.

…interestingly I went and did one once and they said to me, "this has improved from the last time" and I said "well I think I'm just getting better at computer games" ... I think you do know what's coming and you can improve and I just feel more comfortable with doing it.

F1 Norwich 1

I think to do a field test right at the beginning, and to take that as being the definitive field test is wrong…because I think you need to do a test and think, and revise it in your mind what you've done and then do it again. M1 Portsmouth 2

There was some debate about the period of time between VF tests.

I think you need to do a field test and then perhaps a month later do the second one.

M1 Portsmouth 2

Well not if you have a long gap between them. F1 Norwich 2

I've got used to it now. F2 Norwich 2

I don't think it's any different really. F3 Norwich 2

Perceived issues and barriers for successful follow-up care

Some additional themes emerged during the analysis, highlighting a number of areas perceived to be important and potentially representing barriers to successful follow-up.

Communication - Visual field instructions

Regardless of how long they had been attending the glaucoma clinic, patients appreciated having the VF test procedure fully explained to them. It was rare for a staff member to stay with the patient throughout the test, but on the occasions it did happen, patients found the experience reassuring and felt the encouragement helped their performance.

... They say, "Have you done this before?" You say "Yes". And that's it, you're left there and eventually they say, "Have you finished?

M1 Portsmouth 2

I had one about three weeks ago and it was a young nurse and it was a completely different experience. She was professional, polite, kind; she told me exactly what they were doing.... it was almost a pleasant experience. F1 Portsmouth 1

There was discussion about understanding aspects of the testing procedure and how the procedure was explained. For example, some patients expressed uncertainty and felt test pressure would influence their results. Again, explanation and reassurance before and after the test helped.

The staff told me: "don't worry about missing [a light] because it'll come later", so you know you get a second chance. F1 Norwich 1

... if in doubt press the button, don't you? F1 Portsmouth 2

Communication - Explanation of results

Most patients said they had to specifically enquire about their results to find out information about their vision and whether their condition had progressed since the last appointment. Some patients felt intimidated to ask the clinician for feedback as to how they had performed, feeling they were being a nuisance or wasting the clinician's time.

They never discuss the result of the field test unless I ask…

M2 London 2

My wife always says "how did you get on?" and I say "I don't know", and that's one of the problems. M2 Portsmouth 2

I don't think they've got time to listen to you, or they don't appear to, and I don't know whether they would listen…. You feel pathetic asking these questions. F3 Portsmouth 1

Patients may be more inclined to have VF tests more frequently should they be informed clearly about what the results indicate about their prognosis.

I don't mind how many times I do it providing I get a result of the test at that time compared to what the previous one was. Is there any improvement? Is there any downgrade? M1 Portsmouth 1

Communication - The patient-clinician relationship

The quality of relationship with the clinical staff and aspects of patient-clinician communication also emerged as key factors influencing perceptions of the follow-up process.

An apparent lack of personalised care caused unease: there was a sentiment that sometimes the clinician simply looked at the eyes and failed to consider the person's individual needs.

You're not a person, you know, you've just got eyes, they're just going to deal with that and that's it. F3 Portsmouth 1

The experience was seen to be much more bearable if they felt the staff member dealing with them was empathic.

Even buying a chop, you know: if the butcher's interested, it helps doesn't it?

M3 Norwich 1

The opportunity to spend more time with their consultant ophthalmologist was a key factor that influenced whether or not patients were open to visiting the clinic more frequently.

Not [just] for the field test... But I wouldn't mind coming in more to see the doctor.

M2 London 2

Testing environment

The testing environment was another important theme. The dark room, especially if it was warm, made focusing on the tests difficult. Patients felt they performed better in the morning when they were more alert. Ambient noise in the room made it difficult to concentrate; staff members talking and doing the test at the same time as several other patients all had deleterious effects.

I will also say that the staff chatter a lot, which is difficult for concentration; the doors open and close, there's a lot of noise. F1 Norwich 1

I find it difficult sometimes when people [move] about behind you…

M1 London 1

The times that I've had the visual field test done in a room where there's just one [machine], I felt more confident to do it; it was much quieter and more relaxed and it seemed to be a lot quicker too. F3 Norwich 2

I think having the quieter atmosphere would generally help I'm sure….just that feeling of slight calm, you can relax more and then it probably would be a lot quicker because maybe you're not going to miss as many [lights] as you haven't got other distractions. F3 Norwich 2.

The idea was raised that routine VF testing could be carried out in a more convenient location. Some patients had previously visited a local optometrist to carry out a VF test for the purpose of assessing their legal fitness to drive. On the positive side, patients liked the convenience of doing so and described a better testing environment. Conversely, they questioned the competency of the staff, the quality of the equipment and the information trail back to the hospital.

The principle of having routine tests done locally is acceptable providing they are trained.

M1 London 1

That way you would be there, dealt with by people you know probably more intimately…you're in a more relaxed environment…

M1 Norwich 1

I would be concerned about how often the machine was calibrated to get an accurate reading.

M2 London 1

Is the information going back to where it matters in my notes? Things do get lost, and will someone actually look at the test?

M1 London 2

Some felt they had built up a level of trust with the hospital eye service and would therefore prefer to have VFs conducted in this environment.

I've been here for quite a while now and I like coming to them: I don't want to go anywhere else. F1 London 2

I would feel the same because it's a matter of trust. M2 London 2

Clinic constraints -Waiting times

Waiting times were a major concern at all locations. The standard time taken per visit was estimated to be two hours, although the wait was often unpredictable. Established patients were used to the wait and tried not to let it affect them but they still found the system frustrating. Patients were scared of missing their slots and, therefore, would not leave their seat in the waiting area.

No way I'm going to nip off ... especially as now I'm on my own, no way…. just even nipping off to the [bathroom] because you think, 'He's bound to call me. I can sit here for an hour and he'll call me the minute I go to the [bathroom]. F2 Portsmouth 1

Although it was repeatedly acknowledged that the clinics were very busy, which had the knock-on effect of increased waiting times, patients felt they were getting adequate treatment overall. It was suggested that there was a trade-off between longer waiting times and higher quality treatment:

I think that's a very fair price to pay for the fact that you're being dealt with in a UK centre of excellence. There's a trade-off in that you're getting state of the art treatment but the price is you've got to sit around for it. M1 London 1

Clinic constraints - Travelling to the clinic

Several sub-themes emerged including issues with long distances to travel, avoiding rush hours, travel costs and travelling alone.

I think the problem is because I live nearly an hour away, for me the nearest hospital is an hour away… F2 Norwich 2

Taxi is the only way I can do it now. You know, I can get to the station by bus and possibly with help to get on the train but it's not easy…..It's horrific, frightening. M2 London 1

Tiring journeys to the clinic and late clinic appointments were also sometimes perceived to have a negative effect on VF test performance.

I think if you did the eye check later in the day, you know, if your eyes were tired, it might make you feel [that you] wouldn't see so well... F2 Portsmouth 1

Clinic constraints - Scheduling appointments

The scheduling of appointments was a major concern: often the systems were so overbooked that patients were unable to make their next appointment at their clinic visit.

You can only make an appointment six weeks in advance. You used to get a twelve month appointment letter just after you had been for an appointment; now its six weeks before you are due. M2 Norwich 1

Often patients would receive an appointment only to have it cancelled just before the clinic was due to take place. This was not only frustrating to people who had made arrangements for their appointment, such as asking a friend to accompany them or arranging cover for sick spouses, it caused concern that their appointment was to be at a much later date than the clinician had originally requested.

"So if you've been given a six month appointment and it's cancelled, and you're not given another one, you ring up and then they say "oh we can't give you an appointment now until October". That was 10 months. Now if your consultant says 6 [months] and it's 10 and something's gone wrong with your vision in between, you have no way of telling." F2 Portsmouth 2

Patient recommendations

At the end of the focus groups, patients were asked to recommend changes to improve their follow-up care. The recommendations were similar across all locations and the most popular suggestions are displayed in table 2.

Table 2: Patient recommendations for improving follow-up care.

Patient Recommendations	
1.	Less waiting and clinics running to time.
2.	Flexible booking and changing of appointments.
3.	To have a calmer, quieter environment in the visual field room with less people doing the test at the same time.
4.	To modernise the visual field test.
5.	To have more continuity of care by seeing the same clinician at each visit.
6.	To receive better communication from the clinician.

Discussion

Data from this study supports evidence from elsewhere that patients find VF testing more laborious and demanding than other vision tests[20]. Nevertheless, patients were willing to complete more VF tests on the guidance of their clinician, as ultimately they were prepared to do whatever it took to preserve their vision. Thus, patients may tolerate more frequent VF testing during the first two years of their follow-up care as recommended by the research literature[4 5] and some clinical guidelines[24] . Patients commented that it took time to feel comfortable with the test procedure, and that multiple attempts were needed to gain an accurate representation of their vision. These viewpoints complement existing evidence showing that performance can improve considerably during follow-up due to gaining experience with the testing process[25].

There were, however, a number of additional themes that emerged from the data which identified areas that could represent potential barriers to successful glaucoma monitoring. Patients felt that the environment in which they completed the VF test was linked to how well they were able to perform the task, with staff members talking loudly, the number of people in the room, and the time of day all listed as important interfering factors. These views coincide with other evidence showing that the environment, the technician and the time of day do have a significant influence on measurement variability from VF tests[26]. Fatigue, a topic mentioned frequently throughout the discussions, has also been shown to affect performance as test duration increases[27].

Patients highlighted the importance of effective task communication for influencing their VF test performance. Prior evidence has shown that the quality of instruction given before the VF test can significantly affect subsequent estimations of VF defect severity[28 29]. Patients also felt

that it was essential to have the task explained to them properly, even if they had been attending clinics for some time. Having a staff member in the room whilst they carried out the test was found to be reassuring. These findings reiterate the idea that ensuring that the task demands are communicated clearly and effectively before every VF test, and being on hand to alleviate any concerns or questions that the patient may have, may help maximise the quality of the data gained from the assessment[29-31].

Other discussion points relating to communication were also raised repeatedly throughout the focus groups. Patients felt that many clinicians treated them as an 'eye' rather than a person, with those staff members who took a more individualistic and empathic approach viewed favourably. Notably, patients felt that they had to ask explicitly about their results in order to learn details about their own condition. Evidence has shown that that the patient and clinician's views of their condition are not always aligned, which may be due to miscommunication or misinterpretation of key information on both parts[32]. By explaining the results in a clear, simple and concise manner, the patient will inevitably improve their understanding of their condition, which in turn could influence how well they respond to important aspects of their follow-up care. For instance, it has been shown that the way in which clinicians communicate with the patient can influence future adherence to medication[32]. It has been suggested that clinicians underestimate the importance of effective communication to the patient [11], and in one study examining patient expectations for eye care, the emphasised areas were all related to communication and interpersonal manner [33]. Providing better information about the purpose of VF testing, what is required of the patient, and their results and general prognosis could be vital for improving attendance for VF tests or for the subsequent quality of data obtained. Perhaps developers of SAP ought to think about ways in which the complex measurement of the VF could be easily presented and

communicated to patients. It is important to note that some patients associated more frequent testing with worsening vision, which caused some distress. Thus, should patients require more frequent tests at some point in their care, it is also vital to involve the patient and explain reasons for the decision.

Excessive waiting times and difficultly booking appointments were also major concerns. In particular, patients worried that appointment cancellations could extend the interval between tests beyond what was recommended by the clinician, therefore leaving them exposed to undetected disease progression. It is known that whilst clinicians select appropriate monitoring intervals, hospital-initiated rescheduling is a major challenge to appropriate follow-up[7 34 35]. Moreover, it was typical for patients to wait at the clinic for hours in order to complete multiple vision tests, causing frustration and tiredness which some perceived to influence their subsequent performance. Potential solutions could involve conducting only the VF test during short independent appointment slots, or carrying out tests at a more convenient location. However, such strategies would involve further investigation as to their overall cost-effectiveness and should address other associated practicalities such as travel (a significant contributor to total patient costs[36]) and the information trail back to the hospital.

Previous research has relied on statistical analysis or computer simulations to help determine the most effective VF monitoring strategies for patients with glaucoma. This is the first study to use qualitative methods to investigate the patient's own perspective on their follow-up. Studies focusing on the patient's perspective in glaucoma, particularly with regard to the perceived effects of the disease on their day-to-day activities, have typically relied on questionnaires [13]. However, questionnaire responses can be restricted by the wording of the items and provide little opportunity for clarification or elaboration. This study allowed

individuals to contextualise their experiences and expand on particular points and themes, encouraging discussion about topics a certain patient may not have otherwise introduced or attributed to glaucoma without the encouragement of another[18]. The notion of the "expert patient" is beginning to be endorsed with regards to other chronic conditions, with focus groups demonstrating potential as a forum for the development of more effective management strategies[37-39]. Furthermore, patient groups have aided the development of health education programmes for age-related macular degeneration[40]. A systematic review of patient centred randomised controlled trials suggests there may be some benefits associated with involving patients with chronic disease in programmes geared towards better educating service users and devising general training for health professionals[41]. Future work that encourages more patient involvement may therefore help devise the optimal strategies for glaucoma follow-up and also help better inform both patients and health professionals about the condition.

This study has its limitations with findings attached to the viewpoints of the groups who took part. Efforts were taken to reduce bias by involving multiple research sites- however, these were all geographically limited to the South of England and (excluding the London groups) involved patients of Caucasian ethnicity. Therefore the findings may not necessarily translate to a wider population. Moreover, initial patient selection was made on recommendation of consultants at the clinics and our selection process did not monitor reasons for non-participation. People who choose to volunteer for focus groups are likely to be articulate and confident; they may also be more motivated to take part due to having more severe disease or holding strong opinions about a certain area of their care. Furthermore, participants were aged 60 years and older- younger service-users may have differing views and experiences that also warrant investigation. The study was initially designed to involve 6 focus groups across 3 locations and so no direct decision was taken to cease data collection; however, similar

themes and sub-themes continued to emerge in the latter focus groups and so it is likely that 'data saturation' was achieved. Furthermore, some of the focus groups were small (one consisting of only 3 participants) due to late cancellations but this is not a major limitation due to the number of focus groups that took place [42]. Also, some biases could have been introduced during interview and analysis due the preconceived ideas held by the experimenters about the areas of importance, although care was taken to adhere to expected practice by following the COREQ check-list for focus group research[22].

A number of important themes did emerge that give an insight into clinic visits and VFs from the patient's perspective, and could help inform patient centred care in glaucoma. Although patients appeared frustrated by a number of aspects of their follow-up, they ultimately accepted that some compromises had to be made in order to save their eyesight. Some of the viewpoints illustrated in the focus group discussions may in part explain why research-supported guidelines about more frequent VF testing are not being implemented effectively in clinical practice. A holistic approach that embraces patient opinion may therefore be vital to help devise the most effective strategies for follow-up care in this chronic disease.

Conclusion

This is the first study to use qualitative methods to examine patient opinion about the glaucoma clinic experience and VF tests. Although patients found the VF test onerous, they accepted it was important to their overall vision assessment. However, a number of actionable points were raised which were perceived to impact the effectiveness of follow-up care, including distracting testing environments, and hospital constraints relating to excessive waiting times and appointment booking. Some patients also expressed particular concerns

about the VF technology used and the quality of test instructions. Anxiety associated with increased testing in the absence of clinical explanation was another theme. Ensuring that glaucoma monitoring is as clinically and cost-effective as possible will inevitably require the confidence and cooperation of the patient. Addressing some or all of the perceived barriers highlighted in this study should help deliver more efficient strategies for VF monitoring in glaucoma.

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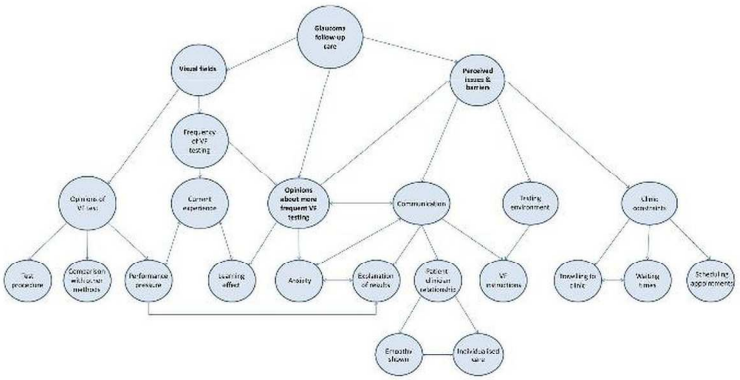

Coding tree showing main themes and sub-themes that emerged from the analysis, and how the categories relate to each other.

Coding tree showing main themes and sub-themes that emerged from the analysis, and how the categories relate to each other.
165x90mm (300 x 300 DPI)