Title: Adherence to ocular hypotensive therapy: Patient health education needs and views on group education

Running header: Health education for glaucoma treatment adherence

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Conflicts of interest

None

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ABSTRACT

Background: We sought to understand the health education needs of patients with glaucoma with particular regard to adherence to glaucoma treatment and to examine their views of group education.

Methods: Using a health promotion approach to health education, 27 qualitative interviews with new and established patients on glaucoma treatment were conducted. Health promotion is defined as way of strengthening people's capacities to control and optimise their own health. The interviews were transcribed then analysed thematically.

Results: Nine categories of health education needs were identified from the transcripts: To understand glaucoma, To understand their diagnosis or understand the difficulties in giving a diagnosis, To understand the implications of eye drops, side effects and how to renew them, To feel confident to put in eye drops, To put the condition into perspective – to know how to manage their risk, To be able to ask questions of the clinicians, To be able to navigate the health care system, To understand and be able to manage own adherence behaviour, To know where to get other sources of information. The majority of patients had something positive to say about group education and about a half said they would attend if they were offered the opportunity.

Conclusions: A health promotion approach identified a wide range of patient centred health education needs regarding adherence to glaucoma treatment. Group education will be attractive to some patients. Clinicians could use the health education needs thus identified to guide the development of either group or single delivery based educational intervention to improve adherence. However they need to be aware that when developing a group intervention that attention will need to paid to making the education relevant to the circumstances of each patient.

Key words: glaucoma; patient adherence; patient education; health education; action research

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INTRODUCTION

Glaucoma is the leading cause of permanent blindness and partial sight worldwide[1,2] with an estimated 60.5 million living with glaucoma in 2010 increasing to 76.2 million by 2020 as the global population grows older.[2] As in other long term conditions, there is a tendency in patients with glaucoma not to follow prescriptions as prescribed.[3,4] Olthoff et al. (2005) found from their evidence based review that between 5-80% of patients did not adhere to their prescribed medication.'[4] The range of proportions of patients who did not adhere arose from the different definitions and methods of measuring adherence. The extent to which patients with glaucoma continue to take eye drops as prescribed without discontinuation has also been shown to be poor. [,5,6,7] For the purpose of this paper, adherence is defined as the degree to which medication taking behavior 'corresponds with agreed recommendations from a health care provider'.[3] Poor adherence to therapy is considered to be a contributory factor in the progression of glaucoma. [8]

There is a great deal of research that has investigated factors that affect whether patients instil eye drops as prescribed. Four reviews of the literature demonstrate the cause of non-adherence to glaucoma medication to be multi-factorial. [4,9,10,11] However while this research is useful, it is not set in the context of identifying health education needs as a precursor to developing an educational intervention to improve adherence.

Educational interventions to improve adherence can be delivered to single or groups of patients or a mixture of both. A systematic review found group education to have an equivalent impact as individual education on patient glycaemic control in type 2

diabetes[12] and another review reported that there was some evidence to indicate that it increases self-empowerment, quality of life and satisfaction with treatment in patients with type 2 diabetes.[13] Only two studies could be located where it was clearly indicated that an intervention was group based education for patients with glaucoma but neither report that the interventions are based on empirical research on patients' health education needs and both were unclear about the impact on patient outcomes including adherence.[14,15] There is also a dearth of research on how patients' view group education. In other educational studies to improve adherence to glaucoma treatment, it is also not reported as to whether interventions are based on an analysis of patients' health education needs.[16,17,18] Further research is required therefore to investigate patients' health education needs regarding adherence to glaucoma treatment and to examine patients' views on group education as preliminary work to developing a group intervention.

In this article, we present findings that originate from an action research project that consisted of a collaboration between patients, health professionals and university researchers that sought to develop a group based educational programme to improve adherence to glaucoma eye drops. Action research is defined as a participatory and cyclical process which aims to advance knowledge while executing an improvement in health care practices. The work presented here was the first stage of that work and aims to understand the health education needs of patients with particular regard to adherence to glaucoma treatment and to examine their views of group education.

METHOD

Qualitative research methods were selected to enable an in-depth exploration of patients' health education needs regarding the promotion of adherence to glaucoma treatment and their views on group education. A strength of this approach is that through open-ended questioning participants' understanding can be elicited. For the purpose of this study, health education is defined as 'any planned activity designed to produce health or illness related learning'[19] and we took a health promotion approach to

health education. Health promotion is defined as a way of strengthening and optimising people's capacities to control their own health.[20] Proponents of this approach argue that when people are empowered through patient led learning they are more likely to take action to enhance their health.[19] Patient led learning is defined as that learning which is determined by the patient as opposed to being decided by the health care professional. Arguably, patient led learning is likely to make the content of educational programme more relevant to the needs of patients. The study received research ethics approval (Reference number: 09/H1008/4). All participants gave informed consent prior to participation in the study.

Sample and methods of data collection. The method of sampling was purposive. We set broad inclusion criteria: 1. Out-patients, 2. >=18 years of age, 3. Diagnosed with chronic open angle glaucoma or ocular hypertension or normal tension glaucoma 4. Newly diagnosed and established patients thus giving access to experiences along the continuum of patients that would be useful to know in the development of an educational intervention, 5. Prescribed hypotensive eye drops. Exclusion criteria were: 1. Angle closure glaucoma, diabetic retinopathy, allergies to ocular medication, and 2. Unavailability of interpreter.

We collected data from patients with glaucoma from glaucoma and general out-patient clinics. A cross section of people were approached initially to take part including those of different ages, sex, ethnicity (defined as white, black or other), socioeconomic backgrounds (defined by employment) and progression of disease (defined as new and established patients) in order to grasp a range of perspectives. We did not set out to predetermine the numbers of patients in each of these categories. To fix 'a priory' the sample size will serve to restrict the ability to respond to the data according to what is being found. This would be counterproductive to one of the strengths of qualitative research which is its flexibility and adaptiveness. As we progressed the emerging patterns of data determined who should be interviewed. Patient recruitment for interviews stopped when data saturation occurred, that is, when no new information on the themes was forth coming.[21]

The aims of the interviews were to identify patients' health education needs in terms of adherence to eye drops. Patients were given a choice to either be interviewed at home or in the clinic. Drawing on an health promotion approach[20], open-ended questions were asked about:

- what type of information would be useful for patients' to know about glaucoma and how this related to adherence,
- their attitudes to eye drops, that is, whether they thought eye drops were effective, whether they personally need and instil eye drops,
- whether they had been taught how to instil eye drops and how they evaluated their competence, and
- the type of support that they needed in order for them to understand their condition and to help them to instil their eye drops.

The interviewer was allowed to ask questions in an unscripted manner in order to follow up comments made by patients. This is a strength of qualitative research because it means that the findings are reflective of the patients' agenda as much as the researchers'. We also asked them about their views on group education and whether they would attend such an event. All the interviews were carried out by a research assistant who was a trained nurse and not involved in the clinical care of patients.

Rigour Several strategies during the research were employed to ensure rigour. Some of these have already been discussed: a flexible approach to sampling, and the concurrent collection and analysis of data. Another approach was member checking.[22] Member checking is defined as gaining research participant feedback on the accuracy of the researcher's interpretation. This was achieved by relating back or summarising the meaning and content of what the participants had said at the time of interview. Rigour was also demonstrated by feeding back patient interview transcripts to the management group consisting of professional and patient representatives who oversaw the project for their insight into elicited themes.

Data analysis. The digitally recorded data from the patient interviews were transcribed verbatim and loaded onto NVivo 8 QSR which is a qualitative data analysis program that assists with non-numerical data indexing, searching and organising.[22] Data analysis was carried out concurrently with data collection thus also allowing for an iterative and responsive approach. The transcripts were read and reread by the university researchers in order to encourage familiarity with content and to gain an overview of emerging patterns in the data. The data of each transcript were inspected for any indication of health education needs and views on group education. These were coded line by line and similar codes were grouped into themes. The themes constituted nine health education needs and an additional theme on group education.

RESULTS

Twenty seven particpants were interviewed (Figure 1). There were slightly more women than men interviewed (52%). Forty four per cent of participants were in the 60-69 age bracket, and most were retired (63%) and newly diagnosed with the previous twelve months (63%). Eighty nine percent of the particpants were white, with only two black participants and one classed as other race (Table 1). The interviews lasted between half to one hour. Those who refused to be interviewed cited not wanting to be bothered or being too busy for their non-particpation. The Results are first organised as per the nine health education needs:

1. To understand glaucoma
2. To understand their diagnosis or understand the difficulties in giving a diagnosis,
3. To understand the implications of eye drops, side effects and how to renew them
4. To feel confident to put in eye drops
5. To put the condition into perspective – to know how to manage their risk
6. To be able to ask questions of clinicians
7. To be able to navigate the health care system
8. To understand and be able to manage own adherence behaviour
9. To know where to get other sources of information

The tenth theme discusses patients' responses to group education. To avoid the criticism of anecdotalism, illustrative quotes and examples are provided of the full range of

viewpoints. Direct quotes will be found in the text. The codes succeeding each quote indicate the patient interview number.

Insert Figure 1 and Table 1 here.

To understand glaucoma

Patients felt that they ought to be told about glaucoma and how it was treated so they can take action to help themselves. While at the most, some of the patients interviewed knew glaucoma was 'high eye pressure' others had completely wrong explanations for its pathology and risk factors. Patients described not being aware of the dangers of glaucoma, what it did to them and complained they were told simply they had glaucoma and little else. A few patients argued that had they known what glaucoma did to their vision they could have taken preventative action against progression. As one patient reported: "…you know, they don't explain, but if they (patients) know it's to reduce the pressure in your eye to stop them going blind I think they might remember" Pt. 01. The data demonstrates therefore that there is a need in this sample to be informed about glaucoma because it helps patients to make sense of their condition and, thus, to understand the implications of their condition if it were left untreated. In other words, it provided them with a justification for instilling their eye drops.

To understand their diagnosis or understand the difficulties in giving a diagnosis

Furthermore, while most patients knew their diagnosis, there were a small group of patients who did not understand why it had taken or was taking a long time to make a diagnosis. As one patient describes:

> "…nobody actually said to me ' you've definitely got glaucoma', they just kept saying you've got, the pressures are increased in your eyes. It was only over time I was getting letters back, copies of letters that were sent to my GP (general practitioner) that did say I had glaucoma on it." Pt. 04.

Additionally, a few reported they had been given conflicting information about their diagnosis when they were seen by different clinicians that they found confusing.

Patients therefore need to have their diagnosis explained or reasons provided as to why this is not yet possible.

To understand the implications of eye drops, side effects and how to renew them

Related to the above concern, patients appeared to know little about their eye drops and the side effects of treatment. A common pattern which emerged from the data was that some patients had been unaware of the side effects of eye drops (a red eye which lasts for about three weeks) and as a consequence had mistakenly stopped putting them in. A few patients did not tell their doctor and continued to non-adhere for months. Some patients felt strongly that had they received education they would have understood the consequences of non-adherence. For example one patient explained: "I just said the drug was no good…I wasn't using it, but if I had enough information, I would be using that drug, even if my eyes are reddish" Pt. 13 [23, p.19]

Personal motivating reasons for adherence focussed on their beliefs about the efficacy and outcomes of instilling eye drops. One woman expressed concern about the toxicity of eye drops. She was sceptical about all medicines which lead directly to her non-adherence as she stated:

> "…I was reluctant to take, I'm… I'm …I seem to sort of, um, don't do very well with drugs, I always feel queasy and, or, you know, if I take antibiotics and things like that. And I didn't want to take statins 'cause I know they… and I have an idea that these pills, these drops that they put in your eyes, they're…sort of antihypertensive ones aren't they, they bring your blood pressure down which kind of thing, err, I maybe…. I don't know, err, I'm a bit suspicious of them [laughs] …So, err, I …I mean obviously they've got to do their business and they've obviously got to be toxic…. But, err, yeah, I … I just don't do these pills and medicines." Pt. 07.

Apart from her beliefs, her understanding of the purpose of eye drops was confused and incorrect. In contrast, patients who claimed to be adherent could not understand why

other patients would risk losing their eye sight by not putting in their drops. In other words these patients were motivated by having positive beliefs and also thought the outcome of instilling eye drops would be positive whereas the woman described above had negative beliefs in the efficacy of drops and also evaluated the outcomes negatively. These beliefs appeared to be linked to how much they knew about glaucoma and its treatment. However, it should be noted that some patients were adherent without having this knowledge.

Lack of knowledge of side effects was frequently associated with having no or inaccurate information about the daily timing of eye drops, and how and when to renew eye drops, altogether, this could result in an impediment to adherence as observed among some patients. It appears therefore that en educational programme would need to include information about the implications of eye drops, side effects and how to renew them.

To know where to get other sources of information

In order to overcome this lack of information, some patients had sought information from the internet and, generally, stated that they found the information useful, as typified by this comment:

> 'I found it [the internet] useful for the fact that I knew what glaucoma was…but unfortunately the Doctors are very busy, so they said 'oh well, you've got glaucoma and we're gonna treat it, gonna give you drops, keep it under control and I'll see you in three months'. And before you know where you are you're out, and you think 'what do you mean? What does he mean?' Pt. 11.

Only one patient reported accessing the website of the International Glaucoma Association. This demonstrated a need in the sample in how to get further reliable information on glaucoma outside of the hospital eye clinic.

To put the condition into perspective – to know how to manage their risk

Furthermore, a few patients appeared to be either excessively anxious about their condition or blasé about its consequences as demonstrated in the following quotes:

> "Um it's just a word to me. Do you know what I am saying?.... It doesn't really mean a lot to me. You know, I'm not worried about the word or the disease you know – as long as I can see…I think that's my only concern…" Pt. 09.

> "… this book I've got, well I didn't buy it because of glaucoma and it's a good thing I didn't…I went though this medical book and started crying because this woman had glaucoma and her eyes looked like two fried eggs in the picture…and so there's a lot of scary bits about it, you know?" Pt. 10.

These personal assessments of the severity of their condition coupled with other issues discussed above could leave some patients vulnerable to over or under precaution in terms of their eye drops which reinforced their adherence behaviour. This suggested that patients need to understand the medical plan of care so that they, for example, to understand their target pressure and how they could contribute to achieving it, where possible.

To be able to ask questions of clinicians

The interview data revealed that some patients were passive in their relationships with healthcare professionals, unable to explain their needs and appeared to receive less support from professionals. For example, a patient discussed his lack of understanding of medical terminology which in turn prevented him from asking more questions:

> 'He said 'we'll keep an eye on it, your pressure's 17' which didn't particularly mean anything to me at the time. The unfortunate thing is, if you're with somebody … and they tell you something, and its something you haven't got a clue about the subject, and what you tend to is not know what to ask, you've no sensible questions'. Pt. 11.[23, p.19]

In contrast, some patients reported how they were confident in asking questions and were able to build rapport, able to explain what their needs were and gain the

information they needed to successfully manage their condition. There appears a need to help patients to know and feel confident in asking questions.

To be able to navigate the healthcare system

Another related issue was that patients commonly reported concern at the postponement of routine follow up clinic appointments. More referrals from optometrists to hospital eye services have been made in the United Kingdom (UK) since the introduction of the NICE (2009) guidelines.[24,25] However, many patients were reluctant or baffled about how to complain and did not do anything about it. Those that tried do something, report contradictions in how different parts of the systems perceived the severity of their condition. One man reported how he felt concerned when a secretary at a specialist hospital had told him he did not need an early appointment whereas his local consultant had told him he did. This served to discourage or de-motivate some of them with regards to adherence to treatment. Having the knowledge and skills to challenge or navigate the health care system to achieve their goals seemed important to some of the patients interviewed.

To feel confident to put in eye drops

In the case of the study sample, patients reported objective difficulties in instilling eye drops and remembering to put them in. Additionally, in some instances, patients reported they initially or still did not have the confidence to perform these tasks. One patient stated:

> "I mean it becomes like cleaning your teeth in the end I'm quite sure. But it's just developing that skill and it just would have been quite nice to have somebody, you know, going, don't worry it will come right…" Pt. 07.

While some patients mastered the skill of instilling eye drops relatively easily others expressed concern that they were not taught how to instil eye drops at the hospital. A patient told how he convinced himself for the first two months that forgetting the eye drops was alright and he put this down to not feeling confident immediately to put in eye drops and by not understanding the implications of the condition. For those patients

who could not instil their drops, carers were often employed to instil them. However, this dependence left patients vulnerable to non-adherence when carers were unavailable.

Many patients forget to instil the eye drops for various reasons. They frequently expressed an inability to incorporate this new behaviour in their routine for they had not yet adapted their routines and lifestyle away from home to include the instillation of eye drops. For example, one patient stated:

> "Oh aye, I've forgot already, yeah … just the odd night. You know, it just depends what I've been doing or if I've been out or something like that. I come in and I've been a bit tired and I've just put me head down and realised the next morning I didn't put them in…" Pt. 16.

Arguably, patients need to be taught to be proficient in (or need someone to assist with) putting in eye drops, and supported with remembering to put them in and incorporating them into their lives.

To understand and manage own adherence behaviour

In our sample, while some patients had managed to work out for themselves how to incorporate eye drop instillation into their routine and were in a position to maintain positive behaviour, the quotes in the previous section show how some were or had been non-adherent. The reported on going difficulties and length of time if at all to resolve their difficulties suggests that patients need assistance in identifying and implementing adherence behaviour.

Patient views on group education

The majority of patients had something positive to say about group education because they saw it as a place to share ideas and have a discussion with other patients. One patient argued: 'Well I think if you're in a group then people will come up with questions which you might not have come up with. And that would be one advantage I suppose.' Others identified it would be good for people who lacked confidence or who were at

home alone, 'it has advantages for people who are, em, lack confidence and , em, well are frightened… if they're on their own with nobody to do anything for them… Pt 14. Others thought that they would be able to see how they themselves coped with glaucoma compared with others as one patient described: 'Err- it would be nice to hear about other people and how they cope… You know, like see who is worse off than me, how do they cope on a daily basis'. Pt 09. While many patients could identify advantages to group education about half said they would not actually attend group education suggesting that 'it was not for them', that they felt it would not be useful or they would not be able to attend because of work.

DISCUSSION

By taking a health promotion approach to health education, we have identified several health education needs from patients' perspectives.[19] There appears to be a range of needs from understanding the diagnosis, the condition, the treatment and side effects, to being motivated to instil eye drops, to have confidence and skills to instil eye drops, to perceive and have the ability to perform a range of adherence behavioural skills to be adherent, to have confidence to ask questions of health care professionals and to be able to challenge or navigate the heath care system, The focus of the health education needs therefore are not only on imparting knowledge but on providing and helping patients feel confident in technical and communication skills sufficient for them to feel empowered to contribute meaningfully to their care.

Group based education appeared to be an acceptable approach to delivering patient health education. We envisage group based education to be one of many approaches to health education; other complimentary approaches include delivery to single patients. It would depend on a patient's needs as to whether delivery of education in a group or individually would be most suitable. Further research is required to investigate whether patients can actually be recruited and will attend group based education. A randomised controlled trial could usefully investigate whether group and single delivery have at least equivalent patient outcomes in terms of adherence.

The establishment of several health education needs for patients on glaucoma treatment regarding adherence will enable the development of an intervention to promote adherence in this group of patients. Other research has found that there is a need to tackle multiple causes of non-adherence. For example, Schwartz et al (2009) found that the number of adherence problems was significantly correlated to non adherence to eye drops.[26] Similarly, Sleath et al (2009) found that the number of reported difficulties with instilling eye drops was significantly associated with reporting less than 100% adherence in the previous week.[27] Multifaceted interventions have also been shown to be effective in general adherence research.[28]

Our study findings are supportive of others that have attempted to identify links between doctor-patient communication and adherence to glaucoma treatment. For example, in the Glaucoma Adherence and Persistency Study (GAPS), it was reported that 34% of questions asked by patients in consultation with their glaucoma physician were about intraocular pressure and disease status, and a further 20% focussed on the medication regimen. [29] These patient issues are similar to some of the health education needs identified by this study. Another finding from GAPS, demonstrates that generally physicians dominate consultations while patients are passive and reluctant to ask questions. [29, 30] These findings are reminiscent of ours in which some patients report finding it difficult to ask about their condition. Other North American studies have also identified poor communication between doctor and patient as a contributory factor in poor adherence.[31, 32]

We found for the first time that not knowing one's diagnosis or the reasons for the difficulties with giving a diagnosis as a contributory factor to poor adherence. This issue with adherence could either be a reflection of the difficulties in giving a diagnosis or because of poor recall on behalf of patients or the problem could lie with the practitioners having poor communication skills which could be compounded by the 'busy-ness' of clinics in the UK. Our findings therefore suggest that an assessment of patients' knowledge of diagnosis needs to be incorporated into an intervention to help patients' place their experience in context and to take appropriate action.

Limitations

Selection bias from the qualitative methodology, the single site for recruitment from a regional eye hospital and small sample size are limitations of this study. A multi-centre, larger sample may have produced more definitive findings but data saturation occurred at the single site which gives credence to the findings. The findings also present a rich cross section of patients' experiences which would be difficult to obtain from quantitative research. Arguably, social desirability bias did not appear to be a huge factor in the responses of the interviewees given the range of reported experiences. We conclude that a non-judgmental approach with open questions allowed patients to respond without undue influence. However, the interviews may have led to introspection which may have in turn led to discussion of needs which may or may not exist or impact on adherence. Further research is therefore needed to investigate whether it is necessary to deliver all the health education needs to achieve adherence.

The study was carried out in the UK where it could be said that there is a tendency for a paternalistic approach to health care which may deny patients' information while at the same time making patients reluctant to ask questions.[33] Given this bidirectional bias, it would appear necessary for researchers developing adherence interventions to first investigate the health needs of their population of patients as it could differ from country to country depending on the pervading professional culture of care.

Other studies have found organisational and provider factors could also influence patients' adherence rates.[31, 34] The WHO (1998) also states that health promotion should tackle structural determinants of health including poor literacy.[35] Therefore, the onus should not always be on the patient to change but also the system and health care professionals.

CONCLUSION

This is the first time that the issue of adherence to glaucoma eye drops has been framed in a health education context. The research found that patients expressed a range of different types of health education needs that appear to be interrelated which need to be addressed in an intervention. Some of the findings are reminiscent of those found in the literature which has considered the risk factors or causes of non-adherence. The qualitative approach taken in this study offers an in-depth insight into patients' behaviour and experiences. The findings suggest that group education will be appealing and appropriate for some but not all patients. Altogether, findings suggest that group delivery will need to cognisant of patients' individual circumstances so that they are able to apply the knowledge and skills thus acquired to their own situation. Group based education also needs to be tested to observe whether it is at least as equivalent in effecting patient outcomes as education delivered to single patients.

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