

Problems and needs in daily self-management of patients with glaucoma: A mixed-methods study

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INTRODUCTION

Glaucoma is the second leading cause of blindness in Europe and in the world¹. In 2011, the prevalence of patients diagnosed with glaucoma in The Netherlands was 74.600. In that same year, 18.300 patients were newly diagnosed². Due to demographic ageing, the number of newly diagnosed patients and patients who will need care is expected to rise over the next decades³⁻⁷.

Glaucoma is a chronic, asymptomatic slowly progressive eye disease in which the optic nerve is damaged due to elevated intraocular pressure (IOP). This elevated IOP results in a severe and irreversible pattern of visual field (VF) defects and blindness⁸. Visual impairment and the perspective of visual impairment have a significant impact on health- and vision-related quality of life, daily wellbeing and functioning⁹⁻¹¹. First-line therapy takes the form of ocular hypotensive eye drops and relies on achieving a reduction in IOP⁸. Consistent IOP lowering is associated with reduced risks of developing optic nerve damage and preventing its progression^{12,13}. However, achieving sufficient IOP rates can be hindered by poor adherence to therapy

Previous studies have reported that adherence fluctuates between 23% and 60%, due to a wide scope of definitions and various assessment methods that have been used¹⁴. Currently, during medical visits at an outpatient ophthalmology clinic of a Dutch academic medical centre, some patients cannot name their medication nor frequency of instillation correctly. Therefore, healthcare professionals question whether patients can manage their disease and adhere to their medication. Specifically, improving education has been seen as a key aspect in changing adherence behaviour¹⁵⁻¹⁸. A survey by Hoevenaars *et al*¹⁹, did not find an overall improvement in adherence with better education, but found certain factors to positively correlate with adherence, including knowledge of glaucoma and fulfilled information needs. A Cochrane Review of interventions regarding adherence to ocular hypotensive therapy concluded that existing interventions may improve adherence, but did not provide conclusive evidence to support any particular intervention, due to methodological issues²⁰.

In general, studies using multifaceted interventions including education and behavioural change were effective to improve adherence²¹. In particular self-management support has been applied in a variety of settings and in various chronic diseases. The content of self-management support might differ across conditions, yet the key feature is to increase patients' ability to deal with daily consequences of their disease to maintain quality of life²².

Although self-management support has been proven to be effective in chronic diseases, it remains unexamined in glaucoma. Therefore, a more comprehensive understanding of the complexity about patients' problems and needs regarding self-management is needed, in order to develop a self-management intervention and thereby to increase effectiveness of glaucoma care. With regard to treatment, there is a growing awareness that interventions should be tailored to patients' needs. Therefore, we used the model of van Meijel *et al*²³, which provides structure for development of evidence based nursing interventions, starting with the patient's perspective. This study aims to investigate problems and needs of patients with glaucoma using daily ocular hypotensive eye drops regarding daily self-management. The ultimate aim of this study is to improve the quality of nursing care and to ensure the effectiveness of the initial therapy.

Research questions were:

1. What are the problems of patients with glaucoma using daily ocular hypotensive eye drops regarding daily self-management?
2. What are the needs of patients with glaucoma using daily ocular hypotensive eye drops regarding daily self-management and what is necessary to support these needs from the patients' perspective?

MATERIALS AND METHODS

Design

A mixed methods study was conducted to capture detail of problems and needs in daily self-management. This study used a sequential explanatory design, consisting of two distinct phases²⁴. The quantitative data provided a general picture of problems, while the qualitative data explored potential needs in more depth.

Statement of Ethics

The study was presented to the ethical review board of the UMCG, which did not find further approval necessary. We certify that all applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed.

Participants

The target population in this study were patients with glaucoma attending an academic centre for consultation. Each year, approximately 3.300 patients with glaucoma visit the outpatient practice. Patients with primary open-angle glaucoma (POAG), receiving first line treatment were invited to participate to describe a range of perspectives. The selected inclusion criteria (Table 1) ensured that patients had used drops for ≥ 1 year allowing analysis of longer-term behaviour. In descriptive research it is not standard practice to perform a power analysis and detect a sample size. Therefore, participants were selected assuming a convenience sample among all patients who visit the clinical outpatient practice between March and October 2014.

The primary researcher checked patients' medical records. Subsequently, an ophthalmologist identified and gave permission to contact patients. Eligible patients (n=54) were informed by the primary researcher through an information letter and a questionnaire delivered by post.

Additionally, a part of these eligible patients were invited to participate in an interview after their clinic consultation, provided that the primary researcher was available. Those patients received an information letter about the interview delivered by post. Patients were contacted by telephone to verify participation in the interview after one week. Informed consent was obtained from all participating patients.

Outcomes

Data were collected about problems in daily self-management, based on the components of the Attitude-Social influence-self-Efficacy (ASE) model²⁵. The ASE model states that behaviour can be predicted by intention, which is determined by an individual's attitude towards behaviour, social influence, and self-efficacy expectations. The ASE-model has been used extensively to identify determinants of health behaviour²⁶⁻²⁸. Additionally, overall self-management was assessed to investigate self-management knowledge and behaviour.

For the qualitative part of the study, outcomes were based on the components of the ASE-model and included needs in daily self-management.

Demographic data, such as education, were obtained from the questionnaire. Medical data, such as VF loss were obtained by reviewing the patient record.

Procedures

Questionnaire

No questionnaire was found specific for assessing daily self-management in patients with glaucoma. Therefore, one was developed for this study. Contents for the questionnaire were extracted from relevant literature (Table 2). Questions were adapted to glaucoma and original response-options were maintained. Subsequently, an initial 84-items questionnaire was developed.

Content validity was confirmed by computing the Content Validity Index (CVI)²⁹. Five experts assessed relevance of each item to concepts of the ASE-model. The experts were selected according to their knowledge of glaucoma or methodological issues related to questionnaire development. Items were removed if the I-CVI score was $\geq .78$, unless items were clearly related to the ASE-model³⁰. Thus, 15 items were removed. The S-CVI/Ave was .94, indicating an acceptable content validity within concepts of the ASE-model³¹. The questionnaire was pretested on one patient, and did not have to be adjusted considering difficulty, comprehensibility or duration. After review of this expert panel, a final 69-item questionnaire was composed.

Reliability coefficients (Cronbach α) were calculated for each of the domains (Table 2). When subscales had sufficient internal consistency ($\alpha \geq .70$), items were reported as results of the total subscale. Otherwise, items were reported as individual items³².

The questionnaire included several concepts:

Attitude

- Knowledge was assessed by four items on an 8-point scale.
- Affective- and cognitive attitude was based on one item involving four different 5-point scales.

Social influence

- Frequency of potentially supportive behaviour was assessed by 13 items on a 6-point scale.
- The social norm that patients experience with regard to using eye drops was assessed by one item on a 5-point scale.

Self-efficacy

- Perceived difficulty and -control was assessed by four items on a 5-point scale.

Barriers

- Barriers related to glaucoma were investigated by 19 items using a 4-point scale. Three items contained an additional response option (e.g. unable to perform an activity = 5). One item used a dichotomised response option.
- Barriers related to using eye drops were investigated by four items using a 5-point scale

Intention was assessed by four items using a 5-point scale. Furthermore, overall self-management was assessed by 12 items on an 8-point scale, with 0 indicating high self-management and 8 low self-management

Interviews

A topic list was developed, based on knowledge of experts, preliminary studies and the ASE-model²⁵. This list covered various issues of living with glaucoma, including the impact of symptoms and treatment regimes on everyday life, social support, and hospital visits. Consistent with an inductive approach, guides were updated continuously based on interim results of analysis before the next interview.

Face-to-face interviews took place between July and October 2014 and lasted 45 minutes on average. Interviews were audio taped, conducted in a private interview room and were subsequently transcribed intelligent verbatim³³.

Data analysis

Questionnaire

Since the sample was small, descriptive statistics were calculated to compare responders to non-responders on demographic characteristics using Mann-Whitney U test, Chi-square test and Fisher exact test. P-values of less than 5% were considered significant.

The questionnaire was analyzed, using the Statistical Package for the Social Sciences (SPSS), version 19. Descriptive statistics are presented as median and Interquartile Range (IQR) to summarize prevalence of problems and overall self-management, since these measures overcome the sensitivity to extreme data values.

Interviews

Interviews were analysed using the analytical steps described by Boeije and the QUAGOL guide^{34,35}. Case-based and analytic memos were written after each interview about initial codes being developed³⁶. To ensure inter-rater reliability, the coding process of three interviews was independently conducted by three experts. The process of constant comparison was used allowing codes, concepts and categories to emerge from the data³⁷. After interviewing ten patients, saturation was reached on a conceptual level. Given the complexity in investigating needs, saturation was not reached in detail.

In keeping with the sequential design, data analysis was completed with the findings of both phases integrated in the discussion²⁴.

RESULTS

Patients' characteristics are presented in Table 3. There were no statistically significant differences between responders and non-responders in age ($U=281$; $p=.94$), number of medication ($U=270$; $p=.63$), VF loss ($U=224$; $p=.41$), education ($U=1.5$; $p=.11$), gender ($\chi^2(1,n=54)=.71$; $p=.41$), living situation ($p=.80$), time since diagnosis ($p=.66$) and administration of eye drops ($p=.87$).

Quantitative questionnaire findings

Thirty-nine patients (78%) of the 54 eligible patients completed the questionnaire and outcomes are presented in table 4.

Attitude

Patients indicated to have knowledge of the disease, symptoms and treatment (median 6.38; IQR 1.75). Additionally, patients indicated that using eye drops is moderately pleasant (median 4.00) with a considerably large IQR, indicating major variation in the answers of respondents.

Social influence

Patients had a median score of 1.46 (IQR 0.77), indicating that people in their environment act never or less than once a month supportive for glaucoma care. In contrast, patients declare that important people near them expect that they use eye drops (median 5.00; IQR 1.00).

Self-efficacy

Patients were confident in using eye drops (median 5.00; IQR 1.5). The perceived difficulty towards using eye drops was low (mean 1.00; IQR 1.00).

Intention

Patients expect, want and intend to use eye drops (medians 5; IQR 0). Additionally, patients don't have a problem with using eye drops (median 1.00), however, the large IQR indicates considerable variation in the answers of patients.

Barriers

Patients had no functional impairments or difficulty performing activities (median 1.22; IQR .30). Additionally, patients do not suffer from side effects and drops are not painful or uncomfortable to take (medians 1.00). However, deviations of the IQR of these two questions are large, indicating major variation in the answers of the respondents.

Overall self-management

The median score of the PIH scale was rated at 6.88 (IQR .96), suggesting generally high self-management.

Qualitative interview findings

Five main themes emerged from the transcripts, which explained domains of needs in daily self-management. Table 5 represents relevant quotes.

Experience of diagnosis

All interviewees experienced the diagnosis of glaucoma, in general, to be an unexpected finding. Glaucoma does not cause noticeable sight loss in the early stages, and for some the diagnosis was the first indication that there was something wrong with their eyes. Others were alerted to vision problems when work was affected. Interviewees argued to obtain more information about the course of glaucoma at time of diagnosis. Others suggested an information session at time of diagnosis or an information leaflet referring to reliable websites.

Data demonstrates a need to be informed about glaucoma because it helps patients to understand the implications of their condition if it were left untreated. Moreover, being informed provides patients with a justification for instilling their eye drops.

The impact on everyday life

Two aspects of daily living were commonly reported as having the greatest impact on lifestyle: Decreasing ability to drive and read. Some talked about fears of being no longer able to read. Others reported trying to hold on to their driving licences for as long as possible, using a variety of strategies to reduce the chance of vision problems causing an accident.

These included avoiding driving during darkness, not using parking garages, or only driving routes they know well. However, for some, losing their licence is something what was expected.

Given that many interviewees had coped, perhaps subconsciously, with diminishing visual ability before their diagnosis, most had found a variety of ways of minimising the impact of symptoms on everyday life. These included taking breaks with reading to prevent tiredness, reducing the lighting difference between in- and outside and writing emails in large font size.

Knowledge of glaucoma

Most interviewees knew little about glaucoma or treatment prior to diagnosis. Some of them had self-educated using pharmacy leaflets or websites. However, key knowledge about glaucoma still appeared lacking for most interviewees despite experience of the disease for more than one year. Some interviewees indicated that they have no need for knowledge because 'to know everything doesn't make happy'. However, others identified the need to know main outlines of glaucoma and practical consequences to better understand what is going on.

Using eye drops was mostly motivated by the fact that eye drops have a hypotensive functioning, that it's for you own good and from a perspective that the ophthalmologist 'knows best'. In other words, these patients were motivated by having positive beliefs and also thought the outcome of instilling eye drops would be positive.

For some interviewees drop administration became simple and 'second-nature'. Additionally, forgetting drops appeared to be explained by factors influencing routine. Particular doses to be taken at busiest times of day or doses that failed to fall naturally into a daily regimen, were more 'at risk' of being forgotten. One interviewee expressed the need of information about suitable dosing times.

While some patients mastered the skill of instilling eye drops relatively easily, others expressed concern that they were not taught how to instill eye drops. Some interviewees told that they have been instructed in using eye drops. Others have learnt it from pharmacy leaflets.

However, only two of the interviewees pushed on the inner nose after instilling eye drops, to block the lacrimal drain area and to avoid side-effects. Therefore, it appears that patients need information about the implications of eye drops and need to be supported incorporate eye drops into their lives.

Social influence

Most interviewees don't talk about glaucoma or problems involved with one's close circle of family and friends. Talking about glaucoma was mostly seen as 'nagging' and that it wouldn't be accepted by other people. Another interviewee suggested the notion of not talking about problems because problems are part of everyday life. Others don't talk about glaucoma because they did not feel handicapped or sick. One interviewee commented that he would only talk about glaucoma when he is well prepared with knowledge about disease and treatment.

Visiting the hospital

Most patients were passive in their relationships with health care professionals, refused to ask questions, and received little support from professionals. Refusing to ask questions was considered to be the direct result of the current system, where doctors appeared too busy to have time to provide adequate education. Moreover, seeing different doctors during each consult interferes with asking questions. However, asking questions was also indicated as 'duty of the patient'. Another interviewee indicated to feel stressed before visiting the hospital.

A little interest from doctors, insight into consults and noticing what the eye pressure is, that's what interviewees expect from their consults at the hospital. Others stated that an information leaflet or an overview of the situation would be helpful in order to estimate the seriousness of the disease.

DISCUSSION

By exploring problems and needs in patients with glaucoma, this study makes a contribution for developing a nursing intervention to improve daily self-management. Multiple problems and needs in daily self-management were identified through an extensive analysis of patients' thoughts and feelings. The questionnaire revealed that patients had little difficulty with daily tasks, such as watching television and reading. However, interviewees talked about difficulties with these specific tasks. Patients appeared to need sufficient information about treatment to gain insight into the benefits of treatment, long-term education with feedback and the establishment of knowledge regarding treatment and practical consequences to enable daily self-management.

Quantitatively, self-rated PiH-scores were high. These results agree with the findings of other studies, which also reported a high overall self-management in patients with a chronic condition^{39,40}.

In addition, patients indicate to have knowledge about glaucoma and treatment. However, interviewees raised questions about glaucoma indicating that they knew little about glaucoma and treatment. These findings are consistent with other research regarding knowledge in patients with glaucoma^{41,42}. Moreover, lack of knowledge is frequently cited as a major cause of poor adherence, but increasing knowledge in itself is often not ground enough for improving behavioural change⁴²⁻⁴⁴. A possible explanation for the lack of knowledge may be that patients did not ask questions to doctors since they wished not to be 'difficult' and presuming that there is too little time. The same belief was reported in other studies^{45,46}. Barriers to adopt an active and participatory role in interactions with their care provider were reported by Henselmans *et al*⁴⁷, including 'not wanting to be bothersome', 'the perception there is too little time' and 'remembering subjects only afterwards'.

Although ophthalmologists are closely involved in monitoring patients' course of glaucoma, Hoevenaars *et al*⁴¹ demonstrated that thirty-nine percent of the patients preferred the ophthalmic nurse as provider for information. Therefore, ophthalmic nurses may accomplish new roles, especially in providing information about consequences of glaucoma as part of daily self-management. The findings of this study may be useful to health care professionals in promoting daily self-management.

Additionally, many patients recalled specific needs as newly diagnosed patients. Therefore, changes in clinical practice appear necessary by identifying individual problems and needs in daily self-management as early as possible after diagnosis. Furthermore, knowledge about the most prominent care needs may be used to develop and improve an individually tailored treatment plan.

The current study has several strengths, including the involvement of the ASE-model resulting in a comprehensive understanding of the determinants of daily self-management. Next to this behavioural approach, the mixed methods design offers the possibility to develop a comprehensive understanding of problems and needs, avoiding limitations on a single approach³⁰. Saturation on themes on a conceptual level was reached, despite the small sample. Another strength was the use of a questionnaire, which was adjusted to glaucoma, tested by an expert panel and based on several validated questionnaires.

Some limitations need to be addressed. Qualitative research in particular can be criticized for being generalizable to only the population from which the patients were selected. The relationship between adherence and socio-demographic factors such as age, gender, race, and education is complex⁴⁸⁻⁵⁰. Unfortunately, due to low ethnic diversity and strict inclusion criterion, all patients were white Dutch citizens. Apart from ethnicity, it was considered that the sample selected, provided a reasonable representation of the Dutch population with a wide age and gender range and variety in levels of education. However, the findings might not be transferable to Dutch residents with language difficulties, since these patients were excluded in this study. Another limitation of the study is the potential for response bias, given the 78% response rate. This could lead to selection bias, though non-response analyses revealed no major differences in demographic characteristics.

In summary, multiple problems and needs in daily self-management were classified. In general, problems faced were related to limitations regarding reading and driving. Findings suggest that specific needs should be addressed soon after diagnosis, including sufficient information about glaucoma and treatment to enhance daily self-management. In order to meet patients' needs in daily self-management situational variables should be removed, allowing patients dare to ask questions without feeling troubled. Use of a health behaviour model may facilitate the development of a tailored approach, accounting for individual and age-related differences in daily self-management. The challenge for the future will be to prepare the health care system to provide not only the necessary medical expertise but also daily self-management support. Further research should focus on assessing the value of the questionnaire as an instrument to assess problems in daily self-management and investigating methods by which initial education and advice regarding daily self-management should best be delivered to patients with glaucoma, following the Utrecht's model²³.

ABSTRACT

Purpose: To investigate problems and needs of patients with glaucoma regarding daily self-management, in preparation for the development of a nursing intervention.

Methods: This study utilized a sequential exploratory mixed methods design and included patients with glaucoma, receiving outpatient care ≥ 1.5 year and using ≥ 1 year eye drops. A 69-items questionnaire, based on the Attitude-Social influence-self-Efficacy-model identified problems in daily self-management and patient interviews captured the depth of needs regarding daily self-management.

Results: 39 patients completed the questionnaire and 10 patients were interviewed. Patients showed generally high self-management and reported to have knowledge of glaucoma. However, interviewees raised much questions about glaucoma. Most of the patients indicated that important people near them think that they should use eye drops. However, interviewees don't talk about glaucoma or problems involved. Refusing to ask questions about glaucoma was indicated by interviewees as a result of doctors who are too busy. A little interest from doctors, sufficient information at time of diagnosis and insight into consults is what patients expect from their visits at the hospital.

Conclusions: The questionnaire identified problems, which should be tackled in an intervention to improve daily self-management. Needs in daily self-management included: interest from doctors, sufficient information at time of diagnosis and insight into consults. Professionals can influence these factors in order to improve daily self-management. The findings of this study could facilitate the continued development of a nursing intervention in order to improve daily self-management for patients with glaucoma.

Keywords: Self-management support; glaucoma; Self-care; medication adherence; ocular hypotensive therapy

SAMENVATTING

Doel: Het inventariseren van problemen en behoeften met betrekking tot het dagelijkse zelfmanagement van patiënten met glaucoom, ter voorbereiding op de ontwikkeling van een verpleegkundige interventie.

Methode: Dit onderzoek maakte gebruik van een sequential exploratory mixed methods design en includeerde patiënten met glaucoom die ≥ 1.5 jaar poliklinische zorg ontvangen en ≥ 1 jaar oogdruppels gebruiken. Een vragenlijst met 69 items, gebaseerd op het Attitude-Sociale invloed-Eigen effectiviteit (ASE) -Model inventariseerde problemen in het dagelijks zelfmanagement. De behoeften werden geïnterviewd door middel van een interview

Resultaten: 39 patiënten vulden de vragenlijst in, 10 patiënten werden geïnterviewd. Nagenoeg alle patiënten rapporteerden een hoog zelfmanagement en veel kennis van glaucoom. Echter, geïnterviewden stelden veel vragen over glaucoom. De meeste patiënten gaven aan dat belangrijke mensen in hun omgeving vinden dat ze oogdruppels moeten gebruiken. Daarentegen, geïnterviewden zeiden niet over glaucoom of problemen met glaucoom te praten. Het niet stellen van vragen over glaucoom bleek een gevolg van artsen die het druk hebben. Patiënten verwachten van hun bezoek in het ziekenhuis belangstelling van artsen, voldoende informatie bij diagnosestelling en inzicht in het verloop van hun consulten.

Conclusie: De vragenlijst identificeerde problemen, die in een interventie moeten worden aangepakt om het dagelijkse zelfmanagement te verhogen. Behoeften in dagelijks zelfmanagement waren: belangstelling van artsen, voldoende informatie bij diagnosestelling en inzicht in het verloop van consulten. Professionals kunnen deze factoren beïnvloeden om het dagelijkse zelfmanagement te verhogen. De bevindingen kan de verdere ontwikkeling van een verpleegkundige interventie ondersteunen teneinde dagelijks zelfmanagement voor patiënten met glaucoom te verbeteren.

Keywords: Zelfmanagement ondersteuning; glaucoom; zelfzorg; therapietrouw; oogdrukverlagende therapie

Table 1 In- and exclusion criteria

Inclusion criteria	Exclusion criteria
Outpatients attending the outpatient clinic	Ocular surgical glaucoma procedures capable of affecting intraocular pressure within 1.5 year
Age over 18 years	Inability to understand Dutch or to speak Dutch fluently
Diagnosis of Primary Open-Angle Glaucoma (POAG)	Clinically significant, serious, or severe medical or psychiatric condition
Receiving outpatient care \geq 1.5 year	
Using \geq 1 year daily ocular hypotensive eye drops	

Table 2 Description of the various constructs assessed, with the number of items, source, range and Cronbach's alpha (n=39)

VARIABLE	No. of items	Derived from	Range	Cronbach's alpha
Attitude – Knowledge	4	Partners in Health-NL(PIH-NL) ⁵¹	0-8 ^a	0.75
Attitude – Affective and cognitive attitude	1	Determinants of Lifestyle Behaviour Questionnaire (DLBQ) ⁵²	1-7 ^{b,c,d,e}	0.58
Social influence - Frequency	13	Diabetes Social Support Questionnaire-Family Version scale (DSSQ) ⁵³	1-6 ^f	0.71
Social influence – Social norm	1	DLBQ ⁵²	1-5 ^g	N.A.
Self-efficacy – Perceived difficulty	4	DLBQ ⁵²	1-5 ^g	0.77
Self-efficacy – Perceived control	4	DLBQ ⁵²	1-5 ^g	0.81
Intention	4	DLBQ ⁵²	1-5 ^g	0.58
Barriers related to glaucoma	19	Aberdeen Glaucoma Questionnaire (AGQ) ⁵⁴	1-4 ^h	0.92

VARIABLE	No. of items	Derived from	Range	Cronbach's alpha
Barriers related to glaucoma	3		1-4 ^h Additional response option (e.g. unable to perform an activity = 5).	
Barriers related to glaucoma	1		1-2 ⁱ	
Barriers related to using eye drops	4	Glaucoma Treatment Compliance Assessment Tool (GTCAT) ⁵⁵	1-5 ^g	0.48
Overall self-management	12	PiH-NL ⁵¹	0-8 ⁱ	0.82(51) 0.78

^a Measured on an 8-point scale (0, 'very little knowledge' to 8, 'very much knowledge' or 0, 'never' to 8, 'always')

^b Measured on a 7-point scale (1, 'unpleasant' to 7, 'pleasant')

^c Measured on a 7-point scale (1, 'unimportant' to 7, 'important')

^d Measured on a 7-point scale (1, 'undesirable' to 7, 'desirable')

^e Measured on a 7-point scale (1, 'difficult' to 7, 'easy')

^f Measured on a 6-point scale (1, 'never' to 6, 'at least once a day')

^g Measured on a 5-point scale (1, 'totally disagree' to 5, 'totally agree')

^h Measured on a 4-point scale (1, 'no' to 4, 'always')

ⁱ Measured on a 2-point scale (1, 'No' to 2 'Yes')

^j Measured on an 8-point scale (0, 'high self-management' to 8, 'low self-management')

Table 3 Demographic characteristics

		Participants questionnaire n (%) n = 39	Participants interview n (%) n = 10
<i>Age</i>			
	Mean (SD)	69.7 (8.6)	70.2 (9.1)
	Range	49-84	58-84
<i>Gender</i>			
	Male(%)	23 (59)	6 (60)
	Female (%)	16 (41)	4 (40)
<i>Education</i>			
	Elementary school	3 (7.7)	1 (10)
	Lower education	11 (28.2)	5 (50)
	Middle education	4 (10.3)	0
	Higher education	18 (46.2)	3 (30)
<i>Living situation</i>			
	With partner	26 (66.7)	6 (60)
	With partner and children	3 (7.7)	0
	Living alone	9 (23.1)	4 (40)
	With family	0	0
	With friends	0	0

	Participants questionnaire n (%) n = 39	Participants interview n (%) n = 10
<i>Administration of eye drops</i>		
Self	31 (79.5)	8 (80)
Partner	5 (12.8)	2 (20)
Family	0	0
Home care	0	0
Neighbours	0	0
<i>Time since diagnosis</i>		
New	6 (15.4)	1 (10)
Established	33 (84.6)	9 (90)
<i>Glaucoma severity grading</i>		
Early glaucoma	1 (2.6)	4 (40)
Mild glaucoma	22 (56.4)	0
Moderate glaucoma	6 (15.4)	2 (20)
Severe glaucoma	8 (20.5)	4 (40)
<i>No. of glaucoma medications</i>		
1	14 (35.9)	4 (40)
2	21 (53.8)	5 (50)
3	4 (10.3)	1 (10)
<i>Type of medication cumulative(including multiple therapy)</i>		
Decrease the production of aqueous humor	28 (41.2)	9 (52.9)
Improve outward flow of aqueous humor	23 (33.8)	5 (29.4)
Combined medications	17 (25)	4 (23.5)

Table 4 Results of the questionnaire according to ASE-variables (n=39)

RESPONSE OPTIONS		Median (IQR)	Total respondents (%)	
Attitude^a	Knowledge	6.38 (5.50; 7.25)	38 (97.4)	
Attitude^b	Affective and cognitive attitude	In my opinion, using eye drops is unpleasant - pleasant	4.00 (3.00; 5.00)	30 (76.9)
		In my opinion, using eye drops is unimportant - important	7.00 (7.00; 7.00)	30 (76.9)
		In my opinion, using eye drops is undesirable - desirable	7.00 (7.00; 7.00)	30 (76.9)
		In my opinion using eye drops difficult - easy	7.00 (5.00; 7.00)	30 (76.9)
Social influence^b	Social norm	Important people near me think that I should use my eye drops	5.00 (4.00; 5.00)	36 (92.3)
Social influence^a	Frequency of potentially supportive behaviour	How often does someone act supportive for glaucoma care	1.46 (1.08; 1.85)	33 (84.6)

RESPONSE OPTIONS		Median (IQR)	Total respondents (%)
Self-efficacy^a		5.00	34 (87.2)
	Perceived control	(3.50; 5.00)	
Self-efficacy^a		1.00	34 (87.2)
	Perceived difficulty	(1.00; 2.00)	
Intention^b	I think it is a problem that I have to use eye drops	1.00 (1.00; 3.00)	34 (87.2)
	I expect to use my eye drops every day as prescribed by the ophthalmologist	5.00 (5.00; 5.00)	34 (87.2)
	I want to use my eye drops every day as prescribed by the ophthalmologist	5.00 (5.00; 5.00)	34 (87.2)
	I do not intend to discontinue using my eye drops	5.00 (5.00; 5.00)	34 (87.2)
Barriers^a	Related to glaucoma	1.22 (1.13; 1.43)	37 (94.9)
Barriers^b	Related to using eye drops		
	Sometimes the drops aren't with me when it is time to take them	1.00 (1.00; 3.00)	37 (94.9)
	Sometimes the drops are painful or uncomfortable to take	3.00 (1.00; 4.00)	37 (94.9)
	Sometimes I am out of drops	1.00 (1.00; 1.00)	37 (94.9)
	I suffer from side effects when using my eye drops	2.00 (1.00; 4.00)	37 (94.9)

RESPONSE OPTIONS	Median (IQR)	Total respondents (%)
Overall self-management^a	6.88 (6.46; 7.42)	32 (82.1)

^a Subscale with sufficient internal consistency ($\alpha \geq .70$): items were reported as results of the total subscale.

^b Subscale with insufficient internal consistency ($\alpha < .70$): items were reported as individual items.

Table 5 Table of quotes (n=10)

Quote number	Quote
1	'I was referred by the optician because the eye pressure wasn't good and then they said in the eye hospital: "Well, not too bad", but after two years, the optician said again: "Don't they do something about it?" So, I went back to the eye hospital, it was indeed proved that the eye pressure was high.' (R6)
2	'And then, suddenly: "What's glaucoma?". I am somebody who quickly closes and pinch and I am trying to listen, but then I'm like: "I'm looking it up, at home." When I heard all that information, I was beaten a little off balance. I was not worried. It went past me what the consequences were. That's something I always have. I did not know what it was. The last time, when the pressure was high, I had one or two days like, then it should just get a place and then it was done' (R10)
3	'It sneaks in and you don't actually notice, it does not hurt, it goes not all at once, it goes very gradual.' (R6)
4	'Yes, of course I knew that my eyesight was not good. I had visual field examinations, well, then they say, "That piece falls away and that piece is lost, it will not come back."' (R4)
5	'I requested to go to an ophthalmologist, because at my work, I had to look somewhere once, but then I could not see it!' (R3)
6	'What awaits me in the future? I don't know! I would like to have some more information on this topic. I was hoping I would not become blind... but will perhaps still happen now, but maybe you don't know that either.' (R8)
7	'I don't know how glaucoma arises, due to high eye pressure... If more information becomes available, I'd like to know!' (R9)
8	'Then I went home and looked it up on Wikipedia. That's not necessarily true what it says on Wikipedia, but in general I found out what it was. In my own place, in my own way and then I just give it a place.' (R10)
9	'For example, if you get a new hip, you will have an information meeting about what to expect. It could be that there was such a meeting for glaucoma, and then I would definitely go there.' (R8)

- 10** 'Clear websites, which are in clear language, not in Latin, because half of the Dutch cannot read it. Not too medical, just down to earth and clear about why you should use your eye drops. Especially in the beginning, when the diagnosis is made, you need to have a clear explanation.' (R10)
- 11** 'When I sit at the computer, I close my left eye. I often catch myself there. Then I see it more clearly.' (R10)
- 12** 'I still would like to make music, I can play the piano and studying, discovering new things but that does not succeed.' (R5)
- 13** 'Actually, it might be that certain sharpness, which is not quite right. That lower case letter, the bottom is just of. But it annoys you, because you pay attention to it every time.' (R3)
- 14** 'I'd rather do not drive in the dark and on a road that is not well known and then I have to look over my shoulder but this happens automatically.' (R1)
- 15** 'I have to turn my head a lot, due to that visual loss. And that's tricky. You have less total overview.' (R4)
- 16** 'I avoid parking garages. From that outdoor light you come straight into the parking garage at once, which I find quite annoying.' (R4)
- 17** 'Now that it becomes dark in the evening, I cannot longer drive, because I see nothing. I have to go by public transport. That is annoying; it is a piece of self-dependence.' (R9)
- 18** 'It's been over 20 years that things go on (without a license), so you don't know better. Annoying, but you know it's coming up. Now my eyesight deteriorates a little, but yes, that's the prediction, so you just keep it in mind.' (R6)
- 19** 'Little did I know what was going to happen. I just got the request to use Timoptol. I had no idea what glaucoma was.' (R3)
- 20** 'The doctor said, 'You need to use eye drops.' He wrote a prescription, so I started using them. But I did not even know what the purpose was, my eye sight became worse, so I thought: 'I have to use eye drops.' And that's what I do.' (R7)

- 21 'I did not know what glaucoma was. I did not know other than that you had to learn to live with it. You get it, and there's nothing to do about it.' (R2)
- 22 'I read the pharmacy leaflet of Timoptol when I was diagnosed, that if you don't do something about it, that glaucoma can lead to blindness. Most knowledge I've got from the leaflet.' (R3)
- 23 'The last time they said that the eye pressure was 19, it was actually too high. I searched for it on the internet.' (R10)
- 24 'What can you expect from all of it? Can't you see anything? Is the eyesight getting worse? So bad, that you see nothing? Is that glaucoma: that you really become blind?' (R2)
- 25 'Well, what I understand of glaucoma is that if you do not intervene as soon as possible damage occurs that will never recover. The optic nerve is affected, broken and cannot be recovered. I know very little of glaucoma.' (R8)
- 26 'Perhaps it has also to do with stress, I do not know. That might be so, but, but I have not yet searched for information about this topic.' (R10)
- 27 'To know everything doesn't make you happy. You can think of the worst. I think I have already enough to think about. I don't want more to think about. At some point you can't do something about it, and if my eyesight deteriorates, so be it. I will not have to worry about such matters in advance. If they don't talk about it, then it will OK, that's what I think.' (R3)
- 28 'Does it matter if I knew more about it? I don't need to know everything. I use the eye drops, they're good for me, than I am satisfied. That's the most important thing: To know that the eye drops are important for the eye sight.' (R7)
- 29 'You've come to an age, when you're younger; you want to know more about it.' (R7)
- 30 'I never talk about my problems. Why? It's part of everyday life. You can make yourself ill with talking. If you constantly talk about your problems, then you are getting sicker. Our generation speaks little.' (R4)
- 31 'I want to know the main outlines, allowing me to imagines how it works, about medication or glasses for example. Then you'll understand better what is going on and what they are planning to do. What the responsibility for me, as a patient is.' (R4)

- 32 'I could not find information about the eye pressure on the internet, what the consequences of the high pressure would be. And how you can get the pressure down, I do not know.' (R10)
- 33 'No detailed explanation. They do not need to use medical terms, I will forget. What it means in practice for me. In practice, it means that it remains as it is or it becomes worse.' (R9)
- 34 'I expect that the eye pressure remains low and that's why I run less damage. That's why I do it.' (R1)
- 35 'I expect the drops to lower the pressure. You cannot do without it! That is my only salvation, right?' (R8)
- 36 'They bring the eye pressure down, it worked again, because my eye pressure was low the last time.' (R10)
- 37 'Though using eye drops can be annoying, it's for your own good. And if you don't use them, and it goes backwards, then it's your own fault.' (R7)
- 38 'It shall be necessary, that's why I do my best to do so every day. I simple have to do so.' (R2)
- 39 'I have no opinion about it. The physician has the knowledge and I have confidence in it, nothing more.' (R4)
- 40 'The thing is the rhythm that it has to happen (using eye drops). We never forget that. It is a daily routine, I do not forget. My wife does not forget, even though she reminds me sometimes.' (R4)
- 41 'Then I thought, "Gee, I don't remember", but I have had visitors...' (R2)
- 42 'Sometimes, in the middle of the day, I think, "Gosh, forget those drops, I have to use them". But those on the morning and evening, that's just routine. If something happens in between, and you forget to use the eye drops, but at some point you'll think of it again. I will never forget ' (R6)
- 43 'Then they offered me another drop, but then I had to use the eye drops twice-daily and I did not want to, because then I have to do it during working hours. Well, I'm going to forget that, I'm sure!' (R10)

- 44 'I asked: "There's a lot of time in between, from six-thirty to five hours approximately." And then he said, "But you can skip it and just do it at night." Well, that's never been told. But now I've heard that I can use them in the evening, it's a lot easier.' (R9)
- 45 "'Well," she said, "here's a paper with a picture, so you can see how you need to do it." So I could see what the position was. With a picture you can see how it's done. That is very good.' (R7)
- 46 'It was first displayed and explained how to do it. Then I was allowed to do it myself. I have learned something about it. ' (R10)
- 47 'I've learnt from the pharmacy leaflet how to use eye drops. They have not demonstrated it to me. I hope I'm doing it right!' (R9)
- 48 'I instill the eye drops in front of the mirror. I have learned it from the pharmacy leaflet.' (R8)
- 49 'I do not tell it by myself. I just tell how things are and then it's good for me. They may still have questions, that's fine, but it shouldn't be such a dominant medical conversation, that nagging. The first time, perhaps people would accept it, but in the long run it will hardly be tolerated. I'm well aware of this.' (R4)
- 50 'If it would be worse than I would talk about it. But for now, I say: "If I'm nagging too much, you must say it, and then we talk about something else!"' (R10)
- 51 'If it would come to question, I would tell it, but I wouldn't bring it by myself. I don't make them happy to tell it. If I want to tell something, I need to be well prepared before I talk about it.' (R3)
- 52 'It must have been discussed, but otherwise I don't talk about it. As long as it all goes well ... I do not feel disabled. That is the reason why I don't talk about it.' (R1)
- 53 'There are so many people who suffer from the heart or something else, they are far less on than I am. I have actually nothing. It's in here, huh, (points to eye), you can talk a long time about it, but you will not be cured.' (R7)
- 54 'No, because it is not bothering me, so I will not bother them.' (R10)

- 55 'I do not talk about glaucoma, but I don't push it away. If it occurs in conversation, we talk about it, but otherwise ... why would you?' (R8)
- 56 'I can reach enough people, if necessary. As long as I own can manage it by myself, it has no added value. If I'm really going to experience discomfort or deterioration of eyesight and fewer things can do, I know that I can rely on them, that they will be there for me.' (R1)
- 57 'Maybe if it gets much worse, if I worry a lot or when I'm anxious, I will say: "Guys, I am out of my depth, now it's bad ... "' (R9)
- 58 'There's so much information headed at you. You don't know the questions that you conceived at home anymore. Everything is gone, because you're in an unfamiliar environment and things headed at you are surprising. You're a bit close, you forget things, and you're a bit overwhelmed. That man (the ophthalmologist) can't take off much time for each patient, that's impossible. That's something you can't expect from him. But I find it very enjoyable that he's attending you at the end of the check, just two minutes.' (R4)
- 59 'It was way too busy. I have my pocket diary with me, I write it down exactly. You have every time a different person, which I find difficult sometimes. Every time you have to tell the story again. You have to ask things and that is not directly be interpreted. See, now you're actually just sent away and we have to raise questions: "Would the pain have to do with?". That is not directly told, but you have to ask it yourself.' (R5)
- 60 'If you have to explain it all, what it is, not everyone can quickly understand, that only takes up too much time here if more people are waiting.' (R10)
- 60 'What I find very annoying is that I see someone else every time. No personal contact.' (R1)
- 61 'It's actually not quite a conversation. You can sit down, the eye pressure is measured and it is determined whether the drops have to be adjusted. It's not extensively discussed, because you have someone else every time. You've been waiting so long and I'm glad I'm out again, then it doesn't matter. Sometimes that works as a brake on the questions. But if you ask anything, you'll get a good answer.' (R6)

- 62 'Today you have this doctor, tomorrow you have another. I have nothing to criticize on the contact, but it is very superficial. If they don't trust something, then I assume that they will say it.' (R8)
- 63 'As long as I'm here it's every time another doctor. I do not like it.' (R9)
- 64 'When I came here, I made a list of questions that I was facing and I asked these questions always. I think actually the patient has an obligation to prepare yourself properly prepare to a consult' (R4)
- 65 'I have to come back in two months, then I spend the night before without sleeping because I think it's just lousy job. Then I think: "Will I see it, or wouldn't I see it?". It's awful. Because it's not going well.' (R3)
- 66 'Well, just a bit of interest and what you've encountered recent times. I want them to see the person and not the disease. Because then you show a part of yourself and the doctor hears more. Now they've asked nothing. Actually, if I want to, I can go away without saying a word. Sometimes I wonder what certain schedules involve. You'll find out. Once a year you see the eye doctor and the other half a year, you get a visual field examination.' (R1)
- 67 'I think it's important to hear during the checks how things are with the eye pressure. I find that very important to know.' (R10)
- 68 'At the beginning you'll get some indications, but if it takes a long time, then you go on autopilot. And then I'm like: "Is it all right?" Yes, it's all good, but once again I would like to have a recurrence of the facts that matter.' (R4)
- 69 'Give a clear form to patients with: "If you have any questions, there you can find it on the internet or call." You can have some sort of telephone consultation hour to answer such questions.' (R10)

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