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Development and pilot-testing of patient decision aid for use among Chinese patients with primary open-angle glaucoma

Jennifer W H Shum,[1] Wendy W T Lam,[2] Bonnie N K Choy,[1] Jonathan C H Chan,[1] Wing Lau Ho,[3] Jimmy S M Lai[1]

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[1]Department of Ophthalmology, The University of Hong Kong, Hong Kong, China
[2]School of Public Health, The University of Hong Kong, Hong Kong, China
[3]Department of Ophthalmology, Queen Mary Hospital, Hong Kong, China

Correspondence to
Prof Jimmy S M Lai, Department of Ophthalmology, The University of Hong Kong; laism@hku.hk

ABSTRACT

Background A patient decision aid (PDA) is a tool for shared decision making (SDM), which emphasises patient empowerment. It is useful in chronic diseases and when there are multiple, no best single treatment option. Although SDM is prevalent in Western countries, its use is limited in Chinese societies, where the adoption of a paternalistic approach is strong. Here, we report the development, acceptance and pilot test results of a PDA targeted at Chinese patients with primary open-angle glaucoma (POAG).

Methods We developed a PDA designed for use in Chinese patients with POAG. Recruited subjects were given our PDA. Baseline evaluation included decision conflict scale (DCS), validated glaucoma adherence questionnaires and glaucoma knowledge questionnaire. Subjects were briefed through the PDA and instructed to read it that day. Three to four weeks later, follow-up questionnaire as described above were conducted with the addition of acceptance questionnaires.

Results Data from 65 subjects were available. The PDA was well received among subjects. DCS improved from 48.9±20.4 at baseline to 34.3±20.3 during follow-up, with P<0.01. Validated medication adherence questionnaires and knowledge showed improvement from baseline, which was statistically significant.

Conclusions The use of PDA among Chinese subjects with POAG demonstrated positive reception and acceptance. Evaluation of its initial effects shows improvement in DCS, medication adherence and glaucoma knowledge. The implementation of SDM and PDA among Chinese subjects with POAG is encouraged. Future studies with randomised design and later evaluation time points can further reveal the impacts of PDA among Chinese subjects with POAG.

Key messages

What is already known about this subject?
Application of shared decision making (SDM) and patient decision aid (PDA) in Western countries has been shown to have multiple benefits for patients, for example, greater knowledge, more accurate risk perception and less decision conflict.

What are the new findings?
Pilot testing of PDA among Chinese patients with primary open-angle glaucoma shows good acceptance, with improved knowledge, medication adherence and decision conflict.

How might these results change the focus of research or clinical practice?
There is a potential role for implementing SDM and PDA into regular practice in Asia.

INTRODUCTION

Paternalistic healthcare delivery, which features dominant doctors and passive patients, is becoming obsolete. Shared decision making (SDM) emphasises patient autonomy, informed consent and patient empowerment.[1] Studies have shown that patients usually make decisions based on emotions such as trust rather than medical information. A patient decision aid (PDA) is a tool to promote SDM and solve decision conflict. PDAs can be used when there are multiple treatment options available and where each option has benefits and harms that different patients may value differently.[2]

The International Patient Decision Aid Standards (IPDAS) Collaboration has developed criteria to judge the quality of PDAs (online supplementary appendix 1).[3–5] This includes a systematic development, provision of evidence-based information about treatment options and probabilities, clarification of patients' values, balanced presentation of options and using plain language. A Cochrane systematic review of more than 80 studies shows that PDAs have numerous benefits: greater knowledge, more accurate risk and benefit perceptions, greater comfort with decisions and greater participation in decision making among patients. There is also some evidence that the use of PDA leads to more conservative decisions with reduced choice of surgery.[2]

The use of PDAs is widely adapted in chronic diseases,[6–9] where outcomes for various treatment options may be less certain, offering a wider scope for patient autonomy.

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In contrast, acute decisions are often urgent and may involve the clinician in a more paternalistic role.

Glaucoma is the leading cause of global irreversible but preventable blindness.[10] An estimate of 9 million of global blindness is attributed to glaucoma. The total number of patients with glaucoma is estimated to increase to 79.6 million by 2020. Population studies found that glaucoma disproportionately affects Asians, with Asians accounting for 47% of those with glaucoma.[11] The estimates in 2013 for the number of people with primary open-angle glaucoma (POAG) in Asia were 33.45 million. This is estimated to increase by 16% in 2020.[12] China, with its population of 1.3 billion, has an estimated prevalence of approximately 1% of the population suffering from POAG. This number is expected to rise with increasing life expectancy.

In Hong Kong, although glaucoma is the leading cause of blindness, the general public's knowledge of glaucoma is limited. In a study conducted to investigate the level of knowledge of eye diseases in the Hong Kong Chinese population, only 10.2% could describe glaucoma symptoms correctly, 1.1% described either the anatomy or physiology correctly and 9.6% were able to mention either surgery, laser or drugs as a form of treatment.[13] Treatment choice for glaucoma involves many options and is complex, each with its own pros and cons. Due to the chronic nature of glaucoma, these treatment choices require a level of commitment, be it in the form of compliance or frequent follow-up. We therefore hypothesise that patients with glaucoma would benefit from the introduction of SDM and PDAs.

Regarding the use of PDAs in ophthalmology, the National Health Service has developed a PDA for patients with cataract (online supplementary appendix 2). An open-angle glaucoma PDA has been developed by the Johns Hopkins University Evidence-based Practice Center (online supplementary appendix 3). Although SDM is prevalent in Western countries, its use is limited in Chinese societies, where the adoption of a paternalistic approach is strong. This may be due to inherent differences in Chinese culture and values. To the best of our knowledge, there have been no ophthalmology PDAs designed for the Asian population to date.

Here, we report the development, acceptance and pilot test results of a PDA targeted at Chinese patients with POAG.

METHOD

Development of draft PDA booklet and criteria IPDAS fulfilment

To develop a high-quality PDA, we respected the IPDAS criteria, which mainly addresses clinical content, development process and evaluation of a PDA's effectiveness[3 5] (see online supplementary appendix 1). In terms of content, information was provided on nature of the disease, different treatment options with their pros and cons and clarification of patients' own values. In terms of development process, plain language was used. Six ophthalmology specialists with glaucoma subspecialty training from different hospitals were involved in the drafting of content, with peer review conducted by two senior glaucoma specialists. In terms of effectiveness evaluation, field testing of the PDA was kindly offered by patients from the Hong Kong Glaucoma Patients Association. This led to the addition of common patient concerns regarding different treatment options and a treatment option comparison overview to our PDA. The final booklet consisted of five chapters: background information on POAG (anatomy and disease course); pros, cons and common patient concerns regarding glaucoma eyedrops, trabeculoplasty and trabeculectomy, respectively; and a table overview and comparison of different treatment options. There is also a final section consisting of questionnaires for patient acceptance threshold towards different treatment options (online supplementary appendix 4).

Apart from respecting the IPDAS criteria, local values and preferences have also been taken into consideration in the development process. A local expertise on patient education had developed a PDA targeted at Chinese patients with breast cancer.[4 14 15] A local survey showed preference of booklet presentation method to audiotape–booklet combination and interactive computer programs. Diagrams were preferred to texts, and the preferred method of numerical and comparison presentations were also adopted.[4]

Participants, setting and measures

Recruitment took place at the Hong Kong West Cluster Ophthalmology outpatient clinic, from February to June 2016. Inclusion criteria were adult patients aged 18 years or above, patients with POAG and Chinese literacy. Exclusion criteria were illiterate subjects, subjects who have difficulty understanding our PDA booklet, angle closure glaucoma with any quadrant of angle closure on gonioscopy, history of iridotomy, secondary glaucoma and non-Chinese subjects.

Participating subjects were given a copy of our Chinese POAG PDA. The contents were briefly covered in a 5 min briefing conducted by our research assistant. They then underwent a baseline evaluation, which included demographic information and questionnaires addressing the following areas: medication adherence, decision conflict, glaucoma knowledge and current patient satisfaction with their current treatment and decision. The questionnaires included the following: a validated 10-item glaucoma medication adherence self-efficacy scale (10-GMASS)),[16] the Morisky 8-item medication adherence questionnaire (8-MMAQ),[17 18] the traditional 16-item five-response decision conflict scale (DCS),[19] a questionnaire to evaluate the patient's general glaucoma knowledge and a questionnaire evaluating patient satisfaction with their treatment and decision making adapted from a previous study.[4] The 10-GMASS and 8-MMAQ were translated into Chinese by a bilingual researcher. The translation was reviewed for clarity by another bilingual researcher. For the DCS, an official Chinese version is available for use. For the glaucoma knowledge questionnaire, it consisted of

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12 questions that evaluated core concepts that encompassed glaucoma anatomy, symptoms and pros and cons of medications, trabeculoplasty and trabeculectomy, respectively.

Subjects were then instructed to read through the PDA at home. A follow-up evaluation was conducted 3–4 weeks later via telephone. All above questionnaires were repeated, along with evaluation of the PDA's acceptance and utility. The acceptance and utility questionnaires were adopted from a previous study,[4] which was derived from the Ottawa Health Decision Center questionnaire. It addressed the comprehensibility of components of the draft, its length, amount of information, balance in presentation of options and overall suitability for decision making.[20 21]

Data analysis

Descriptive statistics was used to delineate the acceptability and utility of PDA. Primary outcome include comparison of all questionnaire scores before and after the use of PDA. Paired t-test was used for continuous data, and McNemar's test was used for categorical data. F-test and two-sample t-test were used to evaluate whether baseline factors acted as confounding variables. Statistical analysis was carried out by the Biostatistics and Clinical Research Methodology Unit of the University of Hong Kong. Software used was R (V.3.2.3, CA1, USA).

RESULTS

A total of 78 subjects were recruited into the study. Four subjects declined baseline evaluation after reading through the PDA. Nine subjects declined follow-up evaluation. Thus, data from 65 subjects were available for analysis.

There were 36 male and 29 female participants. The mean age was 67.7±11.1 years. The subjects have been diagnosed with glaucoma for an average of 6.9±5.4 years. Sixty-four subjects currently require eyedrops for disease control, while one subject is medication free after previous intervention. Ten subjects have previously received selective laser trabeculoplasty and four had underwent filtration surgery.

Statistically significant improvement was observed across 10-GMASS, 8-MMAQ, DCS and glaucoma knowledge with findings outlined in table 1. For the 10-GMASS, each question used a scale from 1 to 10, with 1 indicating very confident and 10 indicating very unconfident. Thus, a total score of 10 indicates the best adherence, while 100 indicates the worst. The subjects scored a mean score of 28.6±14.8 during baseline and 20.6±11.7 during follow-up, respectively. For the 8-MMAQ, a score of >2, 1–2 and 0 indicated a low, medium and high medication adherence, respectively. The subjects scored a mean score of 1.9±2.1 during baseline and 1.0±2.3 during follow-up, respectively. For the DCS, the score ranges from 0 to 100, with 0 indicating no decision conflict and 100 indicating extremely high decision conflict. Scores lower than 25 are implementing decisions, while those higher than 37.5 are associated with decisional delay or uncertainty.[19] The subjects scored a mean score of 48.9±20.4 during baseline and 34.3±20.3 during follow-up, respectively. There were a total of 12 questions for the glaucoma knowledge questionnaire. Counting the number of questions answered correctly, the subjects achieved a mean number of 6.3±2.3 correct answers during baseline and 8.8±2.0 correct answers during follow-up, respectively.

Simple linear regression test was used to test whether diagnosed POAG duration was a confounder in the parameters listed above. No statistically significant association was found between diagnosed POAG duration and medication adherence, DCS and glaucoma knowledge. Two sample t-test was used to test whether the patient's treatment experience (eyedrops only or history of laser or surgery) acted as a confounder. For subjects who had received eyedrops only, there was a statistically significant improvement in 10-GMASS (P=0.003), while no such observation was seen with 8-MMAQ. No statistically significant association was observed with DCS and glaucoma knowledge.

The evaluation of patients' satisfaction with their treatment and decision before and after the use of PDA is shown in table 2. A trend of increased satisfaction after the use of PDA can be observed across all questions. Generalised McNemar (Stuart-Maxwell) test was conducted to test the significance of this increase in satisfaction. Significant changes were observed in questions 1, 6, 7, 9 and 10.

The utility and acceptance of the PDA is shown in table 3. Although less patients read each subsequent chapter, 94% of subjects had completed reading the entire PDA. The overall acceptance of the PDA is fair. Sixty-two per cent of the subjects found the PDA to be of

Table 1 Improvement from baseline in medication adherence, decision conflict and glaucoma knowledge

Questionnaire	Result	Score deviation from baseline (mean±SD)	95% CI	P value
10-GMASS	Improved adherence	−19.8±2.0	(−16 to 23.5)	<0.01
8-MMAQ	Improved adherence	−0.8±0.3	(−0.2 to 1.4)	=0.01
DCS	Decreased conflict	−14.5±2.4	(−9.7 to 19.3)	<0.01
Glaucoma knowledge	Improved knowledge	2.5±0.3	(1.9 to 3.1)	<0.01

8-MMAQ, Morisky 8-item medication adherence questionnaire; 10-GMASS, 10-item glaucoma medication adherence self-efficacy scale; DCS, decision conflict scale.

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Table 2 Patients treatment and decision satisfaction before and after patient decision aid (PDA) use

	Before or after PDA	Strongly disagree (%)	Somewhat disagree (%)	Somewhat agree (%)	Strongly agree (%)	P value, (generalised McNemar test)
Among all treatment options, I understand the reasons I am receiving my current treatment.	Before	15.4	61.5	23.1	0	<0.05
	After	4.6	64.6	23.1	7.7	
I feel strongly dissatisfied towards the side effects of my current treatment.	Before	9.2	63.1	24.6	3.1	0.91
	After	6.2	67.7	23.1	3.1	
I feel satisfied with my current treatment.	Before	12.3	61.5	26.2	0	0.27
	After	9.2	63.1	21.5	6.2	
I wonder if other treatment options would be more suitable for me.	Before	9.2	61.5	27.7	1.5	0.99
	After	9.2	61.5	29.2	0	
I was unable to recall the information given by my doctor.	Before	6.2	50.8	36.9	6.2	0.26
	After	13.8	56.9	29.2	0	
I had a hard time making a treatment decision as my doctor was unavailable to answer my questions.	Before	6.2	44.6	41.5	7.7	<0.05
	After	24.6	46.2	26.2	3.1	
I had a hard time making a treatment decision as I did not know how to ask questions.	Before	6.2	40	46.2	7.7	<0.05
	After	21.5	53.8	21.5	3.1	
I had a hard time making a treatment decision as nobody was able to help me make a decision.	Before	7.7	44.6	36.9	10.8	0.14
	After	21.5	53.8	21.5	3.1	
I had a hard time making a treatment decision as I did not know what questions to ask.	Before	7.7	44.6	40	7.7	<0.05
	After	27.7	44.6	24.6	3.1	
I had a hard time making a treatment decision as I did not know what treatment was best for me.	Before	6.2	49.2	32.3	12.3	<0.05
	After	26.2	49.2	23.1	1.5	

optimal length and content, while 35% found it to be too long and 3% found it too short. Sixty-six per cent found the presentation of treatment options to be balanced with no bias towards any particular treatment, while 9% felt the PDA favoured medications, 11% felt the PDA favoured trabeculoplasty and 14% felt the PDA favoured surgery. Sixty per cent of subjects found the PDA enabled them to understand their disease better, while 29% were neutral and 11% disagreed. Eighty-five per cent of subjects found the PDA helped them feel more informed and comfortable about their glaucoma treatment option, while 15% disagreed.

Table 3 The utility and acceptance of PDA

Chapter	Subjects who read the chapter (%)	Acceptance (%) Good/bad
1. Anatomy and physiology	100	55/45
2. Medications	98	61/39
3. Selective laser trabeculoplasty	95	60/40
4. Penetrating surgery	95	65/35
5. Overview and comparison of treatment options	94	68/32
6. Questionnaires on treatment acceptance	94	59/42

PDA, patient decision aid.

DISCUSSION

Our study is unique in its describing the design, application and testing of PDA during glaucoma clinical care in an Asian metropolitan setting and offers insight to the usefulness of PDA in the Chinese cultural context.

Pilot testing of the PDA showed significant improvement in terms of medication adherence, decision conflict and knowledge among patients with POAG. Compliance plays a huge role in the treatment outcome of glaucoma. Studies have shown that nearly half of all subjects started on glaucoma medications will discontinue treatment within 6 months.[22 23] The mean age of our subjects with POAG is nearing 70 years. For elderly patients to have good compliance and dedication requires understanding of treatment purpose, treatment options, advantages and disadvantages that these options carry and the acceptance of possible side effects. Both the 10-GMASS and 8-MMAQ have been

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validated and shown to accurately reflect medication adherence. The 10-GMASS has been shown to be significantly associated with objective electronic measure of adherence. DCS reliably correlates with constructs of knowledge, regret and discontinuance, reliably differentiates between those who make decisions and those who delay decisions. Finally, improving knowledge has been shown to be positively associated with improving compliance.[24]

It was interesting to observe that subjects who have only received eyedrops as treatment demonstrated a greater improvement in 10-GMASS. When compared with those who have previously received additional intervention, subjects on eyedrops only may feel more compelled to improve their compliance. However, this effect was not seen with 8-MMAQ. We hypothesise that this may be due to the 10-GMASS having a more detailed and wider range for scoring when compared with 8-MMAQ.

Our study has a few limitations. The follow-up questionnaires were conducted in 3–4 weeks' time. Glaucoma is a chronic disease, and this is a relatively short time frame to evaluate the effect of an intervention. The follow-up questionnaires were conducted by phone, and subjects would have the opportunity to refer to the PDA when their knowledge is evaluated, which may overestimate the impact of the PDA. This was avoided as much as possible by our research assistant encouraging prompt answers and asking subjects to refrain from referring to the PDA. The study can be improved by increasing the sample size and supplementing ocular characteristics of recruited subjects. There may be a possibility of selection bias. Finally, by choosing a booklet form for PDA, our study does not evaluate the effect of SDM on illiterate subjects, which still constitutes a portion of our patients with POAG.

In summary, this study demonstrates that PDA is well received and accepted in an Asian metropolitan setting. The outcome also highlights the potential benefits that may be reaped by patients, doctors and society alike. Suggestions for future study directions include looking into the impact of PDA on patient with POAG treatment preference, its impact on decision regret scale that reflects satisfaction with the final decision,[25] evaluating the impact at a later time frame and using a randomised controlled design.

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Competing interests None declared.

Patient consent Obtained.

Ethics approval Ethics approval from our Institutional Review Board was obtained.

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