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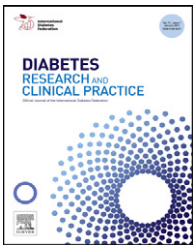

Diabetic retinopathy screening in patients with diabetes mellitus in primary care: Incentives and barriers to screening attendance

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ABSTRACT

Aim: Although diabetic retinopathy (DR) screening is a basic component of diabetes care, uptake of screening programs is less than optimal. Because attendance rates and reasons for non-attendance in an unselected diabetes population are unknown, this study examines incentives and barriers to attend DR-screening.

Method: Four focus groups provided patient-related themes concerning individual decision-making regarding attendance at DR-screening. A questionnaire measuring attendance rates and the influence of several factors was sent to 3236 diabetes patients (>18 years) in 20 Dutch general practices, of which 2363 (73%) responded.

Results: In the past 3 years, 81% of the patients had attended DR-screening. Patients not attending had lower levels of education, a more recent diagnosis of diabetes, and less frequently used insulin. There was no difference in DM types 1 and 2 patients regarding attendance. Patients attending more often visited health-care providers. Patients reported 'knowledge of detrimental effects of DR on visual acuity', 'sense of duty' and 'fear of impaired vision' as main incentives. The main barrier was the absence of a recommendation by the health-care provider.

Conclusion: Knowledge about detrimental effects of DR on visual acuity and recommendation by health-care providers are important, possibly modifiable, factors in the attendance to DR screening.

1. Introduction

Diabetic retinopathy (DR) is an important cause of visual impairment and blindness among adults aged 20–74 years in the USA and the UK [1,2]. About 50–73% of those with visual impairment or blindness as a result of DR can be prevented by early detection and treatment of risk factors, and by photocoagulation [3,4]. Therefore, the International Diabetes Federation guidelines recommend early detection of DR by means of DR screening [5]. Prevention of visual loss has improved considerably during the last decade, especially in northern Europe [6]. However, patient compliance with DR screening is not optimal, as shown by attendance rates ranging from 32 to 85% [8–15].

To increase DR screening attendance, insight into incentives and barriers to retinopathy screening is necessary. Because earlier studies on this topic have a qualitative design, no reliable analyses could be made. However, longer diabetes duration, older age and diabetes-related visual problems are

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associated with screening compliance [14,15]. In the USA, financial barriers are also often reported [7,13,16–18]. Nevertheless, the main barrier for compliance was the patient's belief that they do not have DR [11,19]. Other factors were embarrassment about poor glycemic control and fear of ophthalmological treatment [16,20]. Many conclude that patients' lack of awareness (due to lack of education/information) is the main obstacle to attend a screening program [7,10,12,13,15,16,20].

In view of the major investments in screening and treatment programs, developing interventions to reduce non-compliance should be a priority [6].

The Dutch guidelines for screening for DR recommend a screening interval of maximally 2 years [21]. To evaluate compliance with retinopathy screening in the Netherlands, the present study assesses current attendance rates of DR screening among patients with diabetes mellitus in Dutch primary care. Sociodemographic and clinical factors related to (non-)attendance, as well as the patient's incentives and barriers to screening, are examined.

2. Material and methods

2.1. Development of the questionnaire

In the absence of a suitable tool to evaluate which incentives/barriers play a role in attending DR screening, we used a qualitative approach to develop such a questionnaire [22].

First, the literature was searched for reports on individual incentives/barriers to attend DR screening (e.g., attitude and behavior, incentives and barriers to retinopathy screening, knowledge of visual impairment as a result of DR, and the necessity of screening to prevent this, former experiences in screening, and practical inconveniences). Then, interviews were held with 6 general practitioners (GPs) and with 4 patients with diabetes mellitus to reveal more incentives/barriers that are important to these specialists/patients. Interviews were recorded and transcribed *verbatim*. Analysis of the interviews was aimed at finding all possible issues important for attending/not attending DR screening. Issues were clustered into themes to be used in focus group interviews.

Four focus group meetings were held (in 2006) to evaluate which factors play a role in attending DR screening. All participants were invited by their GP. Informed consent was completed. All meetings were conducted by a professional moderator using a predefined list of topics. The groups were comprised of a mix of attendees and non-attendees in DR screening programs. Separate meetings were held with urban and rural patients (±6 miles/10 km from the hospital where the DR screening was performed). A third focus group consisted of active members of the Dutch Diabetes Association. The fourth focus group consisted of people with a non-western-European cultural background (of Moroccan origin). In this latter group, additional questions were asked about the influence of language barriers and the possible role of different cultural backgrounds.

All group interviews were recorded and transcribed *verbatim*. All incentives and barriers mentioned in the *verbatim* reports were scored independently by two researchers (KvE, YG). Findings derived from the literature, from the individual interviews, and from the focus group interviews were then incorporated into a questionnaire (Appendix).

2.2. Quantitative study

All participants with diabetes mellitus (types 1 and 2) (ICPC code T90) aged 18 years and over, registered in 20 Dutch general practices, received a printed questionnaire in 2008. Three weeks later, a reminder was sent to non-responding participants containing a response card with two questions: 'Did you attend DR screening in the last 3 years?' and 'What was your main reason for doing so?'

A non-response analysis was performed in one of the participating health centers. Of the 160 patients in this center, 33 had not responded. This latter group were telephoned by the nurse practitioner and invited to respond to the above-mentioned questions.

The questionnaire had 3 parts:

Part I: Patient's sociodemographic and clinical characteristics, including age, sex, self-reported height/weight, education level, origin (Western-European vs. non-Western European), type of diabetes, age of diagnosis, self-reported HbA1c, diabetes medication(s), and the location of diabetes care (i.e., general practice or elsewhere).

Part II: Attendance at DR screening: 'attendees' were defined as patients who underwent DR screening within the last 3 years, 'non-attendees' were defined as diabetes patients who had not attended DR screening in the last 3 years. The 3-year period ensures that these patients were 'real' non-attendees taking into account the Dutch guideline of ''minimally one DR screening within two years'' [21].

Part III: Presence of potential incentives and barriers to retinopathy screening. The questions covered all potential incentives/barriers from the schedules derived from the focus group interviews. All questions in Part III were phrased differently in order to be appropriate for attendees and non-attendees. Table 1 presents an example of two typical questions.

3. Analysis

Data were analyzed using SPSS statistical software (version 12.0.1). Descriptive statistics were used to assess the difference in prevalence of screening attendance among the patients. To analyze differences in sociodemographic and clinical characteristics between attendees and non-attendees, we used chi-square tests for categorical data and *t*-tests for continuous data. Chi-square analyses and odds ratios were applied to compare incentives and barriers between attendees and non-attendees.

4. Results

4.1. Qualitative study

The first focus group was comprised of 5 patients (2 men, 3 women, accompanied by 2 interpreters) born in Morocco, the

Table 1 – Example of questions in the questionnaires.

Subject	Question in the questionnaire
Recommendation by care provider	A. Has your GP, internist or GP nurse ever told you that your eyes needed checking because you have diabetes? *Yes/No/I do not know* Is this advice a reason to have your eyes checked? *Yes/No/I do not know* If your GP or internist had not told you that you need your eyes checked because of your diabetes, would you still have had your eyes checked? *Yes/No* B. Has your GP, internist or GP nurse ever told you that your eyes needed checking because you have diabetes? *Yes/No/I do not know* If no, is this a reason not to have your eyes checked? *Yes/No/I do not know* If your GP or internist had told you that you need to have your eyes checked because of your diabetes, would you have had your eyes checked? *Yes/No*
Awareness of possibility to treat DR	A. Can damage to the eyes caused by diabetes be treated? *Yes/No/I do not know* If you answered yes: is this a reason to get your eyes checked? *Yes/No* If you thought that damage to the eyes caused by diabetes could not be treated, would you still have had your eyes checked? *Yes/No/I do not know* B. Can damage to the eyes caused by diabetes be treated? *Yes/No/I do not know* If you answered no: is this a reason not to get your eyes checked? *Yes/No* If you thought that damage to the eyes caused by diabetes could be treated, would you have had your eyes checked? *Yes/No/I do not know*

A, the group who had a DR screening test in the last three years; B, the group who have not had a DR screening test in the last three years.

second group of 4 men and 4 women (active members of the Dutch Diabetes Foundation), the third group of 9 urban patients (4 men and 5 women), and the fourth group was comprised of 8 rural patients (3 men and 5 women).

Tables 3 and 4 present the potential incentives and barriers derived from the interviews and the focus groups.

4.2. *Quantitative study*

The questionnaire was sent to 3236 patients with diabetes mellitus. Of these potential participants, 1891 patients (58.4%) filled in the questionnaire and 475 (14.7%) returned the response card stating attendance (total response for response card 73.1%). For the non-response analysis, 100% of the non responding patients of a large group practice were reached by telephone (Fig. 1).

In total, 1917 patients (81.0%) had undergone eye screening in the last 3 years and 449 (19.0%) had not been screened during that period. Screening attendance rates between the general practices ranged from 58.8 to 91.8%. Non-response (to the questionnaire) analysis ($n = 33$) showed a screening attendance of 78.1% among non-responders which was similar to the attendance among responders in this practice (81.0%).

Table 2 shows that attendees more often had a higher education than non-attendees. Patients with diabetes for 10 years or more and those using insulin were more often frequent attendees. Attendees were more frequently treated by an internist.

In most cases, eyes were examined by means of fundoscopy (74.2%), whereas in 18.1% the eyes were screened by means of fundus photography and 7.7% of the patients did not remember which screening method was used. Examination in mydriasis was reported by 85% of the patients screened by fundus photography.

Incentives that occurred less frequently among non-attendees were: eye screening recommendation made by the care provider, awareness of the detrimental effects of diabetic retinopathy on visual acuity, feeling obliged to attend retinopathy screening, and fear of impaired vision (Table 3). Impaired vision or eye complaints occurred more frequently among non-attendees.

Barriers occurring more frequently among non-attendees were: no eye screening recommendation made by their care provider, lack of awareness of the detrimental effects of DR on visual acuity, screening was not thought to be useful at the patients' age (patients aged $\geq$70 years), no confidence in doctors, no interest or no time to attend, waiting time over 30 min, requiring an accompanying person, and physical disability (Table 4). Fear of the results of eye screening occurred less frequently among non-attendees.

5. Discussion

5.1. *Summary of main findings*

In these 20 Dutch general practices, 81% of the patients with diabetes mellitus (types 1 and 2) attended retinopathy screening. Non-attendees had lower levels of education, shorter duration of diabetes and were less likely to use insulin, or be checked by an internist. The main incentive to attend eye screening is knowledge about the detrimental effects of DR on visual acuity. The main barrier to compliance is the absence of a recommendation by the general practitioner, internist or practice nurse.

Surprisingly, although it is tempting to believe that participants with DM type 2 know more about complications and have a longer duration of disease, we found no difference in attendance between participants with DM type 1 and DM

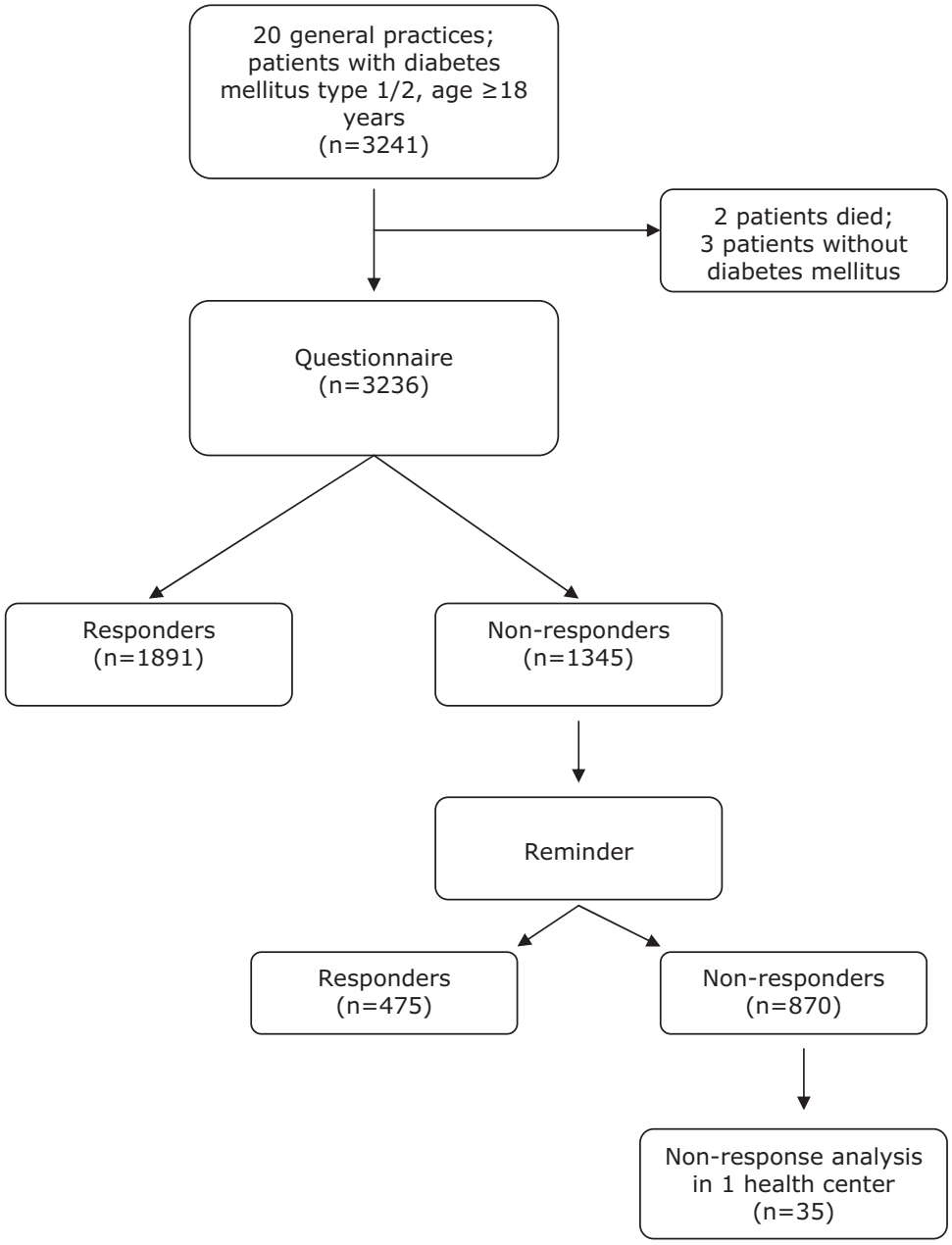

Fig. 1 – Flowchart showing participation in the present study.

type 2. Attendees have more contact with health care providers (lower frequency of no care, lower frequency of GP only, higher frequency of internal medicine). Earlier interventions have shown that better access to health care increases DR screening attendance [23]. Attendees more often expressed a fear of complications as an incentive for screening, and more often feel reassured by the results of the screening. In an earlier qualitative study, patients indicated knowledge about DR affecting the eye but not about DR leading to blindness [12]. More detailed information about complications might help to increase attendance. Although a sense of duty stimulated attendance, guilt related to poor control has been shown to deter patients from attending [12], implying that a positive feedback about attendance could be important.

5.2. *Strengths and limitations of the study, comparison with existing literature*

This study has several strengths. First, the study population is large, representative of the diabetes population in the Netherlands [24], and with a high response rate. Although the attendance rate might be an overestimation due to 26.9% non-responders, non-response analysis showed no differences in screening attendance between responders and non-responders. An attendance rate of 81% is relatively low considering the broad inclusion criteria, but is still probably higher than that in similar studies which reported annual and biannual rates [12,14], except for one study from Scandinavia (98% biannually) [15]. Diabetes care in the Netherlands has improved recently, stimulated by broadly accepted guidelines,

Table 2 – Sociodemographic and clinical characteristics of attendees of diabetic retinopathy (DR) screening, and non-attendees of DR screening within the last 3 years.

	Attendees of DR screening (n = 1589)	Non-attendees of DR screening (n = 302)	p-Value
Sex			
Male	49.3	49.4	
Female	50.7	50.6	0.980
Age (years)			
<50	12.5	16.1	
50–60	26.6	32.2	
61–70	31.3	20.4	
71–80	20.7	17.3	
>80	8.9	14.1	0.459
Education			
High (age > 12 years)	91.6	85.4	
Low (age ≤ 12 years)	8.4	14.6	0.002
Origin			
Western origin	82.7	79.2	
Non-western origin	17.3	20.8	0.176
Type of diabetes			
Type 1	11.5	8.9	
Type 2	88.5	91.1	0.314
Duration of diabetes			
Recent (≤10 years)	55.3	66.8	
Not recent (>10 years)	44.7	33.2	<0.001
Medication			
No medication	14.8	36.7	
Oral medication	56.2	54.6	
Insulin	14.5	4.8	
Oral medication + insulin	14.5	4.0	<0.001
Organisation of patient's general practitioner (GP)			
Single-handed	75.1	77.5	
Practice nurse/health center	24.9	22.5	0.373
Diabetes care			
No care	3.3	13.3	
GP	67.5	76.8	
Internal medicine (with or without GP)	29.2	10.0	<0.001
Body mass index (mean ± SD)	28.6 ± 5.0	28.7 ± 5.6	0.360
HbA1c (mean ± SD)	6.8 ± 1.0	6.9 ± 1.6	0.846

All data are self-reported and presented as %, unless otherwise stated.

Table 3 – Individual incentives to diabetic retinopathy (DR) screening.

	Attendees of DR screening (n = 1589)	Non-attendees of DR screening (n = 302)	Odds ratio (95% CI)
Knowledge and instructions			
Recommendation by care provider	99.4	34.5	341 (164–715)
Knowledge of effects of DR on vision	96.8	90.1	3.3 (2.0–5.5)
Acquaintances with impaired vision due to DR	28.8	22.2	1.4 (1.0–2.1)
Awareness of possibility to treat DR	84.6	77.4	1.6 (0.9–3.0)
Recommendation by friends or family	17.6	20.8	0.8 (0.6–1.1)
Medical considerations			
Impaired vision or eye complaints	30.2	37.3	0.7 (0.6–0.9)
Sense of duty			
Feeling obliged to attend	98.7	91.1	7.7 (4.2–14.3)
Fear			
Fear of impaired visual acuity	60.9	44.4	1.9 (1.5–2.5)
Reassurance by favorable screening results	97.3	95.0	1.9 (1.0–3.6)
Fear that one's own eyes have been damaged	13.5	8.6	1.7 (0.9–3.0)

Data are presented as %.

the introduction of practice nurses in primary care, and ICT-driven prompting. However, the high compliance rate in the present study could be due to the broad definition of 'attendance' (i.e., eye screening in the last 3 years).

The questions (about similar concepts) were phrased differently for attendees and non-attendees (Table 1) in order to avoid information bias by participants having to give answers to hypothetical situations.

Table 4 – Individual barriers to diabetic retinopathy (DR) screening.

Factors	Attendees of DR screening (n = 1589)	Non-attendees of DR screening (n = 302)	Odds ratio (95% CI)
Knowledge and instructions			
No recommendation by care provider	0.6	65.5	0.003 (0.001–0.006)
No awareness of effects of DR on vision	3.2	9.9	0.3 (0.2–0.5)
Belief that one's own eyes are not damaged	86.5	91.4	0.6 (0.3–1.1)
Medical considerations			
Not useful at patient's age (i.e., >70 years only)	1.5	12.9	0.11 (0.04–0.29)
No confidence in doctors	1.4	4.2	0.3 (0.2–0.7)
No impaired vision or eye complaints	69.8	62.7	1.4 (1.1–1.8)
No gain in information from screening results	17.7	15.1	1.2 (0.9–1.7)
Fear			
Fear of results of eye screening	46.7	32.1	1.9 (1.4–2.4)
Fear of eye injury during screening	11.2	8.4	1.4 (0.9–2.2)
Practical inconveniences			
Not interested in attendance	11.1	19.9	0.5 (0.4–0.7)
No time to attend	7.1	14.4	0.5 (0.3–0.7)
Waiting time over 30 min	34.1	50.8	0.5 (0.4–0.7)
Requiring an accompanying person	46.0	57.0	0.6 (0.5–0.8)
Physical disability	25.1	30.9	0.7 (0.6–1.0)
Laborious to make an appointment	28.5	33.0	0.8 (0.6–1.1)
Living more than 6 miles (10 km) from the screening location	49.6	44.4	1.2 (0.9–1.6)
Other			
Religious considerations	55.2	57.2	0.9 (0.7–1.2)

Data are presented as %.

Because of the cross-sectional design, it is not possible to draw conclusions about whether or not participants who indicated barriers will subsequently attend screening. The present study focuses only on the patients' current opinion.

5.3. *Implications for future research or clinical practice*

The main areas for improvement are concerned with knowledge, awareness and instruction, implying that both the main incentives and barriers are related to these topics. Moreover, all these are modifiable factors. Some non-attendees may be inclined to externalize the reasons for their non-compliance, ignoring their caregivers' efforts to stimulate them to attend. However, apart from the waiting time, practical inconveniences were not highly rated barriers (Table 4). Moreover, the large range in screening attendance rates between the practices (59–92%) indicates that practice organisation can probably modify attendance. A systematic review reported that increasing patient awareness of DR and improving provider/practice performance can increase screening attendance [23]. Thus, GPs, internists and practice nurses should focus on information, recommendation and follow-up to encourage attendance in DR screening. However, attendance is also influenced by environmental, cultural and personal factors (e.g., a lack of trust in doctors) which cannot be unravelled via a questionnaire. The barriers towards attendance may also lie within these areas. For those in high-risk groups (such as underserved inner-city areas, and populations using different languages or with financial constraints) not only is active education and encouragement necessary but also facilitation of DR screening by the provision of inexpensive surveys by appropriately trained technicians. Collaboration with community-based organisations in order to reach high-risk groups could be an effective way to increase DR screening [23].

6. Conclusion

Apart from the more personal views on incentives and barriers, effective areas to increase attendance seem to be related to knowledge, awareness and instruction. Thus, even in this population with high attendance, the key to increasing attendance may lie with health professionals raising awareness about the benefits of screening. The practice organisations can play a role by identifying and actively prompting non-attendees to undergo DR screening.

Conflict of interest

The authors declare that they have no conflict of interest.

Ethical approval

The study was approved by the Medical Ethics Committee of the Leiden University Medical Center.

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Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at doi:10.1016/j.diabres.2011.11.003.

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