Patient education on retinopathy

M Rothmann, AH Nyland, L Hammelsvang, L Petersen, G Kirketerp, JE Henriksen*

Summary

This article describes the results of an intervention study considering patient education on retinopathy, aiming to increase knowledge of retinopathy, self-care and self-efficacy.

Fifty patients were randomised to either an education programme or standard follow up in the clinical setting. The patients were followed for two years. Parameters were measured at baseline, and after one and two years. Twelve patients were interviewed after one year using semi-structured focus group interviews. The analyses were grounded in the framework of Steinar Kvale and an approach based on Aaron Antonovsky´s 'sense of coherence'.

Several themes emerged. The main themes in both groups were fear, knowledge and acceptance, but there was a difference in the way in which these themes were described. The intervention group could describe how they used the knowledge in their everyday life. In contrast, the control group indicated knowledge about retinopathy but appeared not to use this knowledge in everyday life. Furthermore, the intervention group regarded prevention of retinopathy as a responsibility shared between themselves and the health professionals in relation to self-care skills, whereas the control group appeared not to take responsibility. The only theme described identically in both groups was 'anxiety' at the time of diagnosis. The quantitative data did not show any significant effect of the patient education.

We conclude that education made a difference to the way in which the patients experienced retinopathy. The intervention group showed 'sense of coherence' by expressing comprehensibility, manageability, and meaningfulness.

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Key words

patient education; retinopathy; nursing practices; sense of coherence; empowerment; evidence-based practice

Introduction

Retinopathy is a common complication of diabetes. About a quarter of patients with type 2 diabetes (T2D) have retinal microvascular changes at time of diagnosis.[1] Furthermore, since the prevalence of retinopathy is increased with disease duration, many patients with type 1 diabetes (T1D) will develop retinopathy during the course of their disease.[2] Numerous risk factors for retinopathy have been established and, besides disease duration, hypertension, dyslipidaemia and smoking have been found to increase the risk of this complication.[2,3] Intervention studies, such as UKPDS and DCCT, have shown that retinopathy can be prevented.[4,5]

In Denmark, screening for retinopathy has been a standard procedure in the management of diabetes for many years. Experiences from the clinical setting have shown a need for guidance and education on retinopathy – education not only in the primary prevention of retinopathy, but also focusing on the secondary stages of the disease.

Authors

M Rothmann, RN, MHS, PhD student
AH Nyland, RN, MScN
L Hammelsvang, RN
L Petersen, RN
G Kirketerp, RN, MPM, MScN
JE Henriksen, MD, PhD
Department of Endocrinology, Odense University Hospital, Denmark

***Correspondence to:** Mette Rothmann, Department of Endocrinology, Odense University Hospital, DK-5000 Odense C, Denmark; email: mette.rothmann@gmail.com

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Aim. The aim of the present study was to evaluate a new nursing practice for diabetic patients with retinopathy. We wanted to determine whether systematic patient education could optimise knowledge of retinopathy, lifestyle changes and self-management. Furthermore, we aimed to evaluate whether the acquired patient knowledge and capabilities could prevent retinopathy progression and ultimately save eyesight.

Patients and methods

Study design. This randomised study used both quantitative and qualitative methods. Patients were randomised to either an intensified educational programme or the standard follow-up procedures in the outpatient clinic. The study period was two years with evaluation at baseline and after 12 and 24 months, whereas focus group interviews were performed at 12 months only. The focus group interviews were semi-structured using open-ended questions to encourage discussion and elicit the meanings, views and experiences of having retinopathy.

Inclusion criteria. Inclusion criteria were: T1D or T2D; aged 18 or more; no or mild retinopathy; not pregnant; Danish speaking; and no other chronic diseases.

Procedure. Patients were recruited from the outpatient endocrinology clinic at Odense University Hospital, Denmark, from 2005–2006. In the nominated period, 132 patients met the inclusion criteria; 50 patients agreed to participate. The main reason for declining was lack of leisure time. Included patients were

Time	Lesson 1 (week 1)	Lesson 2 (week 2)	Lesson 3 (week 3)	Lesson 4 (week 7)
2.30–3.15pm	Introduction, expectations of education	Prevention of retinopathy	Treatment of retinopathy	Everyday life and retinopathy
3.15–3.30pm	Break	Break	Break	Break
3.30–4.15pm	Anatomy and physiology of the eye	Prevention of retinopathy, and self-care	Treatment of retinopathy, cataract, glaucoma, and age-related macular degeneration	Closing discussion

Table 1. Educational programme timetable for the interventional group

randomised to either an educational programme or the standard follow-up procedures in the outpatient clinic. Both written and oral information about the study was given and informed consent was obtained.

Educational programme. The educational programme contained four lessons of 1.5 hours each during a three-month period, as outlined in Table 1. The lessons were given over approximately one year from randomisation. The content of every lesson was well described according to the aims and methods. In addition to retinopathy, metabolic regulation, blood pressure, lipids, cigarette smoking, diet and exercise, the teaching focused on treatment options in relation to progression of retinopathy and time for discussion of psychological aspects. Teaching methods were inspired by Aaron Antonovsky's 'sense of coherence' and an approach using empowerment. Patients' experiences were central in an attempt to strengthen self-management.[6,7] Teaching was seen as a pluralistic approach to evidence-based practice.[8,9]

The quantitative data. Vital signs were measured. Besides height and weight, blood pressure on the left upper arm was measured after a five-minute rest period with an Omron M4 and was presented as systolic and diastolic values. Retinal photography was taken with a TRC-NW6S non-mydriatic camera (Topcon). In brief, after pupil dilatation with Mydriacyl 1% and Metaoxedrin 10%, six photographs of each retina were taken. Subsequently, photographs were graded by a trained ophthalmologist using the classification from the EURODIAB protocol.[10]

Blood samples were drawn in the non-fasting state. Analysis of HbA_{1c}, low-density lipoprotein, high-density lipoprotein, total cholesterol and triglycerides was performed.

Statistical methods. Between-group differences in delta values were evaluated using the paired *t*-test for significance. Data are presented as mean ± standard deviation (SD) or median (range), as appropriate. *P*-values <0.05 were considered statistically significant. All statistical analyses were performed using SPSS statistics 17.0.

Focus group interview. Ten patients from both groups were invited to participate in a focus group interview. The patients were selected regarding age, gender, type of diabetes and degree of retinopathy in a non-randomised manner in order to capture a homogeneous group that represented the total study population. Of the 20 patients invited, six in each group agreed to participate.

The first author performed both interviews at the hospital. Focus group interviews were performed to obtain a wide perspective of topics.[11] Participation gave each patient the opportunity to express his/her understanding and experiences regarding retinopathy. The focus group interview encouraged discussion centred on these views and new topics could be raised. The interviews were semi-structured using an interview guide. They included main questions such as: 'How did you experience getting retinopathy?'; 'Did the instruction/education on retinopathy you received from the nurse cause changes in your everyday life?'; and 'Would you try to explain your wishes for follow up in the outpatient clinic and what offers you would like?' The interviews were conducted in Danish, and the answers were translated into English.

Data analysis. The audiotape recordings of the interviews were transcribed and analysed manually by systematically following the steps drawn up by Kvale:[12]

- Reading though the interviews in respect of developing the meaning of the interview.
- Natural 'meaning units' of the text expressed by the subjects were determined by the researcher. (Table 2 provides examples.)
- Meaning condensation: themes dominating the natural 'meaning units' were restated by the researcher as simply as possible.
- 'Meaning units' were analysed in terms of the specific purpose of the study.
- The essential themes were tied together into a descriptive statement.

Question asked by the interviewer	Respondents' answers	Natural 'meaning units'
How did you experience getting retinopathy and what went through your mind when you were told that you had retinopathy?	'It is very important for me to maintain good eyesight' 'Oh; what is wrong?' 'I often get nervous and worry when things are happening that I do not understand' 'I think you can become blind in the future'	Worried and nervous because of uncertainty Fear of becoming blind

Table 2. Examples of natural 'meaning units' (distinctive psychological meanings) relating to respondents' replies to interview questions

Variable	Control T=0 (n=25)	Control T=24 (n=18)	Intervention T=0 (n=25)	Intervention T=24 (n=19)	*P*-value Δ C vs Δ I
HbA_{1c} (%)	7.41±1.00	7.52±0.96	7.49±1.16	7.56±0.82	0.826
Systolic blood pressure (mmHg)	136.0±18.4	134.1±17.1	128.6±18.5	134.7±17.4	0.283
Diastolic blood pressure (mmHg)	77.5±10.9	79.5±11.5	75.0±10.5	79.3±10.1	0.536
Total cholesterol (mmol/L)	4.66±0.75	4.25±0.74	4.30±0.71	4.11±0.79	0.223
HDL-C (mmol/L)	1.59±0.49	1.92±1.58	1.60±0.53	1.49±0.62	0.209
LDL-C (mmol/L)	2.30±0.70	2.20±0.61	1.77±0.63	2.05±0.54	0.393
Triglycerides (mmol/L)	2.10±2.78	1.57±1.03	2.07±1.50	2.15±1.75	0.157

Values are presented in mean±SD. HDL-C = high-density lipoprotein cholesterol; LDL-C = low-density lipoprotein cholesterol.

Table 3. Results at baseline (T=0) and at 2 years of follow up (T=24) for the control (C) and intervention (I) groups

Ethical considerations. The study was performed in accordance with the Declaration of Helsinki and all participants received oral and written information before signing informed consent. The study was approved by the local ethical committee and the Danish Data Protection Agency. All participation was voluntary and could be ended at any time. Data were kept under lock and key and no outside persons had access to the information obtained.

Results

Fifty patients were randomised; 37 completed the two-year follow up (18 control group/19 intervention group). Reasons for drop-outs were lack of time, illness and death.

The quantitative data. Baseline data (control group T=0 and intervention group T=0) are shown in Table 3. The primary endpoints of the study were to test the effect of an education programme on parameters of lifestyle changes and self-efficacy. The secondary endpoint was to test the effect of the programme on progression of retinopathy. The primary endpoints were tested by applying the *t*-test on delta values in the control group versus the intervention group. No overall differences between the two groups were found after two years of follow up (Table 3).

The secondary endpoint was change in the degree of retinopathy. There were no significant differences between the two groups.

The data did not suggest the possibility that a patient could, for instance, have worsening in the right eye, and at the same time improvement in the left eye. In this situation, the patient would overall be unchanged. To comply with this approach a score system was devised to find the overall changes in retinopathy (Figure 1). Overall, both groups improved. There seemed to be a small difference between the groups, but it was not significant.

The focus group interviews

The themes in the two sets of interviews were nearly identical, but the weighting and description of the themes were different in the groups.

Fear. Fear of blindness was the only identical theme described in both groups at the time of diagnosis. Fear was described as emotional and embodied. Emotionally the patients described the diagnosis as a shock and in embodied terms they were anxious about losing their sight.

'The first thought you get is that eyesight will be lost... The biggest fear is if this should happen,' (Maria, control group).

After intervention, the intervention group indicated that knowledge reduces fear of blindness.

Knowledge. The main theme in the two groups differed. 'Knowledge' was the most significant theme in the intervention group. The group described how knowledge about retinopathy was important in everyday life and how it became embodied. This was indicated by motivation for metabolic control and treatment of hypertension: *'...It was great... we learned something... something we didn't know in advance,'* (Ben, intervention group); and *'...I often think about the fact that I need to consider what I do, what I eat, my blood sugar and blood pressure – and all the other things that in one way or another have an impact on my eyes' condition,'* (Michael, intervention group).

Knowledge about retinopathy was described differently by the control group. The group had knowledge of retinopathy, but could not use the knowledge in everyday life: *'...it might be that you [the professionals] tell people what they need to know when they come to the outpatient clinic... and that there is nothing more to know... It could also be that you do not tell enough... and that we ought to know more... It is very difficult... What do we need to know?'* (James, control group).

Responsibility. The main theme in the control group was 'responsibility for prevention'. The group indicated that the responsibility should be handled by professionals and that they themselves had only a minimum of responsibility for the prevention of retinopathy: *'...You are the professionals. It is up to you to guide us if anything should happen,'* (Anna, control group); and *'...I take it for granted... if something is wrong, you will let me know... I trust my doctor in taking care of my best interests,'* (James, control group).

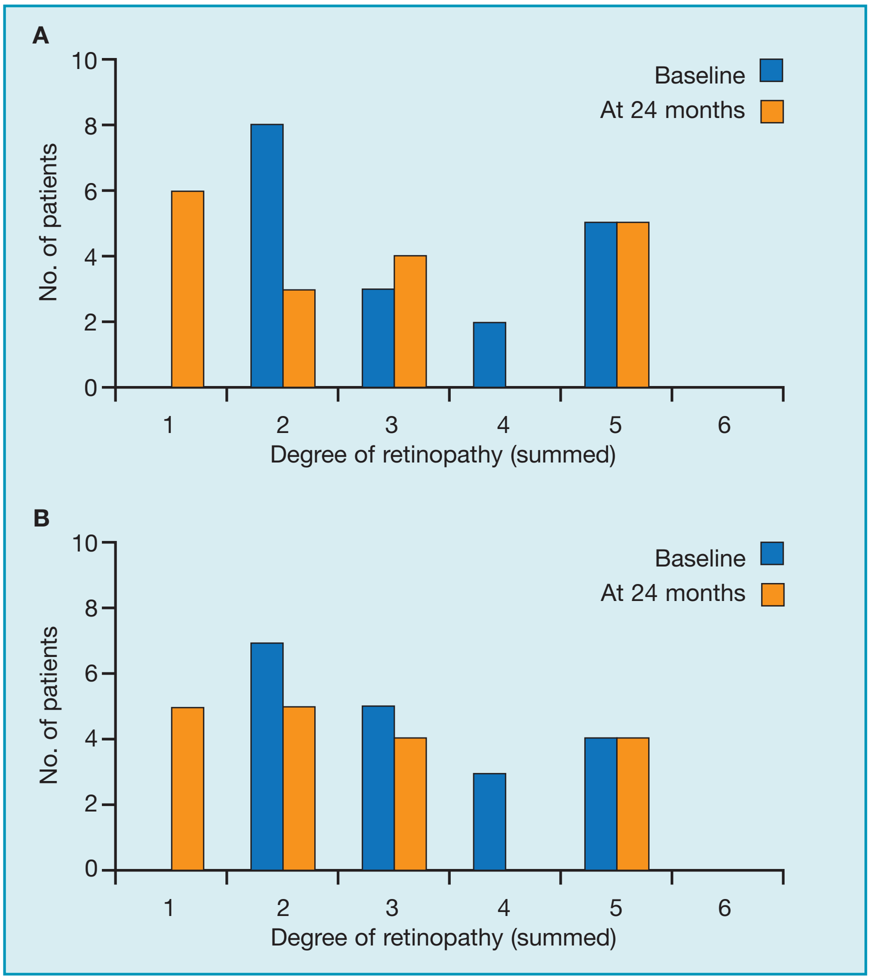

Figure 1. Results: overall changes in retinopathy in (A) the control group, and in (B) the intervention group

The control group indicated that knowledge had not become embodied. The group had knowledge, but they did not act according to that knowledge. When the professionals took responsibility, the patients felt safe, but it did not reduce their fear of blindness.

The intervention group described responsibility for prevention as something shared between the patient and the professional: *'...You [the professionals] keep an open eye [looking for any changes on retina]...'* (Ben, intervention group); and *'...I am the one who has to control my diabetes...'* (Laura, intervention group).

Accept. Both groups described 'accept', but in different ways. The control group was resigned; they felt only a minimum responsibility for preventing retinopathy and did not know how to use their knowledge. In contrast, the intervention group took action and responsibility in the prevention of retinopathy, shown as shared care.

Discussion

The intention of this study was to evaluate whether patient education on diabetic retinopathy could optimise knowledge concerning retinopathy, lifestyle changes and self-care, and prevent progression of the retinopathy. The study has demonstrated the need for patient education in relation to retinopathy and also the need for constantly developing new nursing practices to support and meet the needs of the patients.

With regard to our interview findings, patients who attended education described how knowledge in relation to retinopathy and self-care had an impact on fear and anxieties about blindness. Findings confirmed that knowledge of diabetes and retinopathy, as well as openness to the psychological dimension of retinopathy, strengthens patients' sense of coherence resulting in less fear or anxiety.[13] Moreover, our results illustrated that knowledge of retinopathy, self-care, and self-efficacy in relation to retinopathy are associated with responsibility and motivation to prevent diabetic complications. Patients attending the education programme said that knowledge helped them to achieve better metabolic control. They also said that responsibility for prevention could be shared, arguing that knowledge affects patients' ability to take part in this responsibility.

Conversely, the patients who attended the standard follow-up programme indicated that they had knowledge about retinopathy but could not describe how this knowledge was used in everyday life. These patients said that responsibility for prevention was to be handled by the professionals.

Our findings confirm the results of previous studies. Multidisciplinary patient education has been found to have a positive effect on knowledge of diabetic retinopathy and self-management.[14–17]

However, our quantitative data did not show any significant effect of the education programme. Thus, no significant differences were found between the two groups in relation to prevention or progression of retinopathy. Furthermore, no differences were found in the most important parameters (HbA_{1c} and blood pressure) associated with development and progression of retinopathy.[4,5] In general, it has been difficult to demonstrate change in HbA_{1c} caused by patient education, especially in long-term follow up.[18,19] In the present study, several reasons could influence the findings. Primarily, the small sample size results in lack of statistical power. Furthermore, the patients entering this study were in general well treated in relation to HbA_{1c} as shown in Table 3. All patients were followed in a standardised screening programme.

Education had, according to the patients' statements, a positive effect on sense of coherence, empowerment, self-care and self-efficacy in relation to responsibility, ownership and everyday life with diabetes and retinopathy. Compared to other studies, we did not measure knowledge using quantitative methods.[14,20] Instead, we obtained an insight through interviews on how knowledge about retinopathy was used in everyday life. The main point in this study is that knowledge achieved by patient education seems to be comprehensible and meaningful. Thus, knowledge is translated into everyday life.

Methodological considerations

In terms of generalisability, the study findings should be viewed in the light of other studies because of the small number of patients.[11,21] The study was conducted as a pilot aiming to test the education programme. Statistical power was not calculated and could explain some of the non-significant findings. Furthermore, only one focus group interview was conducted in both groups. A few more interviews would have been preferable in order to find differences and similarities within or between the two groups.

With regard to reliability, the interview's themes and meaning units were discussed with a co-analyst (AH Nyland). The possibility of bias in relation to the facilitator was handled by describing the facilitator's position prior to the interviews and by using the interview guide. Moreover, two colleagues observed the interviews and made notes during the interviews.[21]

It is recognised that the way in which patients talked about the education or the standard follow up in the outpatient clinic may have been influenced by the facilitator in a positive way. However, we are convinced that the value of a sole interviewer may outweigh this possibility, because of the trust and relationship built up.

Clinical implication

Patient education on diabetic retinopathy has an impact on knowledge, self-care, self-efficacy and fear of blindness. Knowledge of retinopathy, its treatment and prevention is important to the everyday life of those with diabetes and retinopathy. Knowledge becomes important with regard to sustaining a sense of coherence in relation to prevention of retinopathy progression. Although patients seem to be well educated regarding diabetes management, the development of mild retinopathy causes fear and anxiety – a fear that motivates the patient to obtain knowledge in order to manage the at-risk situation.

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Declaration of interests

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