Experiences of an educational programme for individuals with blindness caused by diabetes

J Leksell, G Sandberg, K Wikblad*

Abstract

Background: Individuals with blindness caused by diabetes face problems in their daily life that are related to both conditions. Hopefully some of these problems can be solved and simplified through a suitable educational programme.

Aims: The aim of this study was to evaluate whether the educational programme 'I'm the boss' is suitable for blind individuals with diabetes, and to discover whether and how the programme inspired the participants in developing self-management skills.

Methods: An ophthalmologic centre and two medical centres in a well-defined geographic area were screened for blind individuals with diabetes, resulting in the participation of nine individuals in the educational programme. The programme consisted of six three-hour-long weekly sessions based on empowerment and problem-based learning. Empowerment was measured using the Swedish version of the diabetes empowerment scale (Swe-DES-23). After completion of the programme, the participants were interviewed (focus group and individual interviews). The interviews were analysed using qualitative content analysis.

Findings: The evaluation of the educational programme showed that almost half the participants improved their diabetes empowerment in the subscales 'self-awareness' and 'ability to manage stress'. The qualitative data corresponded well with the quantitative data in terms of increasing participants' self-efficacy and knowledge. The learning process was experienced as flexible and the content as stimulating and creative.

Conclusion: It is concluded that the programme seems suitable for blind individuals with diabetes, and in collaboration with others allows space for innovation and self-realisation.

Eur Diabetes Nursing 2006; 3(2): 86–91.

Key words

Empowerment education programme; problem-based learning; blindness and diabetes; self-efficacy; qualitative content analysis

Introduction

Individuals with blindness caused by diabetes encounter a number of problems in their daily life. Self-care activities are found to be difficult and blind individuals with diabetes have to cope with different dilemmas related to both conditions. They must prepare and carry out medical regimes and check blood glucose, as well as deal with other practical and psychosocial problems caused by both diabetes and blindness.[1–3] Lack of knowledge, worry and anxiety may also cause stress.[4] There is a need to facilitate and simplify the lives of blind individuals with diabetes. However, some of the problems can hopefully be reduced through appropriate patient education.

Few studies have evaluated educational programmes for people with both diabetes and blindness. Bernbaum *et al*[5] carried out a 12-week programme that enabled participants to master self-management and blood glucose monitoring. The programme resulted in independent and more effective self-management in blind individuals with diabetes.

Anderson *et al*[6] developed and evaluated a six-week educational programme for individuals with diabetes. The purpose of the programme was to enable patients to gain self-efficacy. The evaluation showed improvements in that respect.

Inspired by Anderson *et al*[6] a Swedish educational programme was constructed. This programme has been evaluated in several groups of patients with type 1 and type 2 diabetes and has been found to be successful.[7] Because little attention has been paid to the group of blind individuals with

Authors

J Leksell,[1,2] RN, PhD, Senior Lecturer
G Sandberg,[1,2] RD, PhD, Senior Lecturer
K Wikblad,[1] RN, FEND Professor

[1]Department of Medical Sciences, The FEND centre for European Diabetes Nursing Research, Uppsala, Sweden
[2]Department of Health and Social Sciences, Högskolan Dalarna, Falun, Sweden

***Correspondence to:**
J Leksell, Högskolan Dalarna, Health and Social Sciences, S-791 88 Falun, Sweden
Tel: +46 2377 84 81
e-mail: jle@du.se

Received: 20 April 2006
Accepted in revised form: 30 May 2006

diabetes, we wished to implement the programme for them. The aim of this study was to evaluate whether the programme 'I'm the boss' was suitable for blind individuals with diabetes, and to discover whether and how the programme had inspired the participants to develop skills for managing their daily life situation.

Method

The study design was an educational intervention with pre- and post- measures using both quantitative and qualitative methods.

Participants

Individuals with type 1 diabetes, 20–65 years of age, with blindness caused by diabetes (visual acuity <0.1) were sought through advertisements in tape-recorded newspapers and letters to the regional ophthalmologic centre, the medical centre's diabetes clinic and the primary healthcare centres in a 7000 km^2 area and with 200 000 inhabitants.

The search yielded 11 individuals (approximately 0.9% of all patients with type 1 diabetes). Seven of those 11 agreed to participate in the programme. Four did not wish to participate owing to haemodialysis (n=2) and a stressful life situation (n=2). Two more individuals indicated great interest in participating and were included in the study, even though they did not fully meet the criteria (one was 77 years old, and the other was found to be diagnosed with type 2 diabetes).

The final sample then consisted of nine individuals (three males and six females), 31–77 years of age, with a mean age of 46 years. Completion of higher education was reported by seven people (i.e. upper secondary level). The mean duration of diabetes in the group was 32.1 years (SD±17.6), and the mean duration of blindness was 13.5 years (SD±8). The mean value for HbA_{1c} before starting the programme was 7.1% (SD±1.0).

Intervention

The empowerment programme was implemented as group education.[7] The programme included six three-hour-long weekly sessions. Problem-based learning (PBL) was used as the educational method. PBL is an eight-step process in which participants solve problems that they have agreed upon in the group. The solutions may either be found in the literature, by asking an expert, by relying on one's own reflections or by using other resources.[7]

The topics for the six weekly sessions were life satisfaction and goal setting, problem solving, coping with emotions, coping with daily stress, social support and motivation. A nurse teacher and a blind person with diabetes acted as facilitators in the group during the sessions.

The programme started with the participants introducing themselves to the group. The facilitator gave a thorough description of the pedagogical method, PBL. Participants were able to invite a lecturer/specialist to the group and to contact a librarian assistant if they wished to record an interesting text. After one week, the group members met to discuss what they had learned and how they had solved the problem. They also reflected upon their newly acquired knowledge and discussed how this new knowledge could be applied to their own daily self-care. After each session, the group process was evaluated (e.g. 'Did we listen to each other?'). For non-sighted individuals, listening and concentration constitute an important part of obtaining new knowledge.

Measures

Self-efficacy was measured using the Swedish version of the Diabetes Empowerment Scale (Swe-DES-23).[8] The Swe-DES-23 is a diabetes-specific empowerment questionnaire which includes 23 items representing four subscales. The questions are constructed as Likert scales ranging from strongly agree (=5) to strongly disagree (=1). The four subscales are: goal achievement and overcoming barriers for goal achievement (10 items), self-awareness (4 items), managing stress (4 items), assessing dissatisfaction and readiness to change (5 items). The items within each subscale were added up and divided by number of items giving a score ranging from 1 to 5. Higher scores indicate stronger empowerment. Crohnbach alpha-values ranged from 0.68 to 0.91 for the four empowerment subscales when tested in 195 patients with type 1 diabetes.[8]

Interviews

Focus group interviews

The focus group interviews took place directly after the programme was completed and lasted from 45 to 80 minutes. The groups were chaired by one of the researchers (JL). To elicit a wide range of responses, open-ended questions were used which dealt with the pedagogical method, opinions about the choice of topics, and their own as well as the facilitators' qualifications. In the course of the interview the researcher sought clarification and used probing, questioning and summarising to confirm comments made. All participants were encouraged to contribute. The interviews were tape-recorded, and then transcribed verbatim.

Individual interviews

A registered nurse with no involvement in the programme inter-

viewed all the nine participants six months after they had completed the programme. The interview guide included questions on self-management problems, goal setting, diabetes and feelings, diabetes and stress, and social support[7]. The interviews began with the open-ended question: 'Why did you choose to participate in "I'm the boss"?' The interviews continued with questions intended to encourage participants to elaborate on their opinions about the different topics described above, e.g. 'You told me that you have no good experience of social support – please tell me how you felt and whether you discussed it during the course'. Follow-up questions were put within all topics for purposes of clarification and to obtain more detailed information. The interviews lasted from 40 to 90 minutes and were tape-recorded and transcribed verbatim.

Ethical considerations

Written informed consent was obtained and the participants were made aware of their right to refuse to answer questions and to withdraw at any time.

The Medical Ethics Committee at Uppsala University approved the design of the study (No 03-024). All personal identifiers have been removed so that the person described cannot be identified through the details given in the study.

Analysis

The results of the Swe-DES-23 subscales were reported before and six months after the educational programme intervention. The differences in empowerment subscales before and after the intervention were described on an individual level as higher (+) or lower (-). Higher scores (+) indicate increased empowerment and lower scores (-) indicate decreased empowerment. Zero (0) indicates that scores in the empowerment sub-scales neither increased nor decreased after intervention.

The focus group and individual interviews were analysed together using qualitative content (manifest and latent) analysis.[9] Findings were reported as a theme, categories and subcategories. The different steps in the analysis are described below:

Step 1: The analysis started with sorting the transcribed text into two content areas: the effects of the programme and the participants' experiences of the programme as such. After this, the text in the two content areas was read repeatedly to obtain a sense of the whole.

Step 2: The text was divided into meaning units and these units were condensed, abstracted and labelled with codes.

Step 3: The various codes were compared, looking for similarities and differences, and then sorted into seven subcategories and two categories, which constituted the manifest content. Two researchers (JL and KW) discussed the analysis to verify that the coding was in agreement with the meaning units.

Step 4: Finally, the underlying meaning, the latent content of the categories, was formulated into a theme.

Results

Evaluations of the educational programme 'I'm the boss' using Swe-DES-23 showed that four of the nine participants increased their *self-awareness* and *ability to manage stress*. Only two individuals increased their *goal achievement* and *readiness to change*. The individual differences in total Swe-DES-23 scale varied between -0.6 and +1.4. Table 1 gives the individual scale differences. The analysis of the qualitative interviews is described below.

The participants' experiences of the programme may be summarised in a single theme: *In collaboration with others allow space for innovation and self-realisation*. This theme was formulated on the basis of two categories and seven subcategories (Table 2). In the following sections, we describe the categories and subcategories. Quotations have been added to give meaning to the text. The quotations are labelled with letters from A–I representing the nine participants.

Inspiring learning climate

The participants expressed that the learning atmosphere was of utmost importance. A climate in which an individual can feel safe, become stimulated to learn more and be creative in finding solutions for self-management is most important for learning.

Safety

The climate in the group was described as very warm and the communication was secure and relaxed. The participants laughed and enjoyed themselves. Reflective discussions and the possibility of sharing feelings with others in the same situation gave a sense of increased security for the members.

'Next time I visit my doctor I'll dare to ask questions. It feels safe for me to speak.' (F).

Stimulation

Participants considered the content of the programme inspiring, in terms of both its cognitive and affective aspects. Cognitive aspects referred to rational thinking, for example, applying facts to different situations. The participants considered the new knowledge to be stimulating. Information was given within the context of the participants' life in a way that made sense to them. Affective aspects referred

to the participants' feelings about and reactions to their diabetes.

'I think the programme has been an important stage in my self-management process.' (H)

'It's important to talk with others in the same situation; it's extremely useful and very very important. It gives me more than if I visit the doctor twice a year, and I get the result from the HbA_{1c}. During this education you get new ideas and ... yes time for each other.' (C)

Participants	Goal achievement	Self-awareness	Managing stress	Readiness to change	Total DES
A	-0.9	-0.5	-0.5	-1.2	-0.6
B	+0.5	0	+0.5	-1.6	-0.3
C	-0.3	+1.5	-0.3	-0.4	+0.3
D	-0.4	-0.4	+1.3	-0.2	+0.1
E	-0.8	-0.2	-0.8	-0.2	-0.1
F	-1.0	+1.8	+1.7	+0.6	+1.4
G	+0.8	+1.0	+1.5	+1.0	+1.2
H	-0.8	0	-0.2	0	-0.2
I	-0.6	+2.1	-1.2	-1.0	-0.2

+ = higher after the programme
- = lower after the programme

Table 1. Individual differences in Swe-DES-23 before and 6 months after the educational programme in 9 participants (A-I)

Creativity

It was of great importance that the participants were allowed to influence the content of the programme, and this promoted positive attitudes in the group. This also helped them to share knowledge and experiences with each other. Most of them were positive about seeking new knowledge. Finally, the participants welcomed the coffee breaks, which allowed them to communicate and share experiences other than those related to diabetes.

'Every week I look forward to visiting the weekly session, to meeting, talking and sharing experiences with my friends in the group.' (A)

Prior to the present programme, the participants had not received any information or education for years, and they suggested the establishment of a patient education and counselling programme at the outpatient clinic. They also wrote a letter to the political board.

Homogeneity

Factors that facilitated a good group spirit were the group size, age range and having the same kinds of problems. The participants were homogeneous in relation to blindness and diabetes, and this was considered both positive and negative. It was positive because it was easy to recognise common problems and to support each other. It was negative because it might reinforce the feeling of 'us against them us belonging to the blind world versus them in the sighted world'.

Self-efficacy

Shared knowledge

The importance of sharing knowledge with others in the same situation was stressed. The shared knowledge facilitated participants in their self-management and inspired them to apply this knowledge to solving everyday problems directly. They also perceived that their new and increased knowledge would influence self-management in the future.

'Earlier I didn't know that a "talking blood glucose meter" existed, and maybe I'll use it in the future.' (A)

'Earlier I couldn't handle unstable blood sugar, when the sugar was high I injected more insulin and when the blood sugar was low I ate. During the sessions I learned from my friends in the group that they had had the same problems and they told me how they handled them, so nowadays I keep a cool head.' (E)

Confirmation

Participants felt that they confirmed each other during the group sessions. They became involved in everyone's strategies to find individual solutions to daily problems and self-management. They listened to each other in a respectful way and spoke about the feeling of 'being somebody'. The participants expressed it in this way:

'Well, now it's confirmed that I'm the one who has the greatest knowledge about my own body. It's not the doctor who should tell me how or what to do.' (G)

Self-confidence

After the education, the participants felt that they 'were their own masters'. One of the participants reflected upon the fact that her mother had always insisted on having control over her daughter's blood sugar levels, which was irritating.

'Before this education programme, I thought it was an insurmountable obstacle, my mother always told

Sub-categories	Categories	Theme
Safety Stimulation Creativity Homogeneity	Inspiring learning climate	In collaboration with others allow space for innovation and self-realisation
Shared knowledge Confirmation Self-confidence	Self-efficacy	

Table 2. Subcategories, categories and theme of the evaluation of empowerment group education in blind individuals with diabetes

me how I should act in different self-management situations, but now I've learned to say: please let me do this by myself, because this is my life. Nowadays I feel much better.' (I)

Participants also pointed out the importance of seeking new knowledge by posing questions to the diabetes team or by reading/listening. One of the group members had problems with a painful shoulder. She read an article, which gave her knowledge and inspired her to start posing questions to the diabetes team.

'Nowadays I have the courage to ask my diabetes nurse about my aching shoulder.' (E)

The participants reflected upon problems and solutions related to their daily life. They gained the courage to discuss and revise the content of the group meetings. The education also gave them ambitions and helped them to gain deeper insight into new possibilities. One example was the possibility to formulate goals.

'Isn't it wonderful that I can set new goals after 30 years with diabetes?' (D)

Discussion

This study has demonstrated that the blind participants with diabetes appreciated the educational programme 'I'm the boss', which used the problem-based learning (PBL) method. The primary objective of implementing the programme was to stimulate the blind participants and provide them with an environment in which they could share experiences with individuals who had similar problems.

When using the Diabetes Empowerment Scale for measuring different aspects of empowerment, we found that the subscales *self-awareness* and *managing stress* were the two aspects that increased after completion of the programme, while *goal achievement* and *readiness to change* did not. This was also verified in the interviews. Most of the participants expressed that, after the intervention, they knew more about diabetes self-management, they were aware that they were their own masters and they had increased their self-confidence.

In the interviews, participants expressed that goal setting was inspiring, but this could not be verified by the DES subscale *goal achievement*. The path from setting a goal to achieving it is very long and probably demands lifestyle changes. The DES subscale measuring *readiness to change* did not show positive changes in more than two of the participants, and this was certainly because a six-week educational programme is too short a period for establishing lifestyle changes. It is known from other studies[10,11] that patients with diabetes-related blindness or visual impairment perceive difficulties with diabetes care activities, and situations requiring advanced self-management.

Through discussions and reflections with others in the same situation, the participants felt that they had improved their knowledge of self-management. They also confirmed each other, which allowed them to articulate feelings, reactions and strengths. The participants felt safe in getting involved in other people's problems in a respectful way, and they appreciated confirmation. This result is in accordance with the findings of other authors,[12–14] who have stated that two key concepts in achieving independent diabetes self-management are reflection and understanding.

Glasgow *et al*[15] found that weak as well as strong social support may be a barrier to achieving satisfactory diabetes self-management. Throughout the programme, subjects identified and discussed various social support problems. As a result of the programme, subjects realised that 'being somebody' had been a strength in relation to both significant others and the diabetes care team. The support established within the group helped participants take an active approach to the development and promotion of diabetes education. For example, they took the initiative and contacted local politicians to make them aware of the lack of education programmes, particularly for non-sighted individuals with a long history of diabetes.

The educational programme took up both affective and cognitive aspects in a structured way. These aspects enabled participants to focus on knowledge that is

important for solving self-management problems. When the problem had been identified, self-efficacy seemed to facilitate individual problem solving.

If increased self-efficacy is of importance for satisfactory self-management, it is important to offer blind individuals with diabetes an adequate educational programme. To be able to identify and solve problems on an individual level, there is a need for flexibility. Problem-based learning is one example of flexible and inspirational learning, assuring the development of thinking patterns relevant to identifying and solving self-management problems.[7]

The climate in the group was experienced as creative. This facilitated the learning process that enabled them to search for answers to questions they had posed.

Another factor was the fact that they were living in an equal health situation, and thus recognised one another's problems. Daily problems were first and foremost related to the two conditions, i.e. blindness and diabetes, and not to type of diabetes or age. This may explain why the two participants who did not meet the criteria for sample inclusion did not seem to impact the result.

It seems more important that the group members are more homogeneous in relation to problems regarding diabetes and blindness than to age or type of diabetes. Lazare[16] and Perry and Rosenfeld[17] reported that patients with comparable conditions made good use of meetings with groups of people with similar problems. However, the participants pointed out that it was not entirely positive that only non-sighted individuals were included in the programme. They considered that this caused a feeling of 'us versus them', as if being blind meant that they belonged to one world and the sighted to another.

Because few studies have focused on blind patients with diabetes, it is difficult to compare our results with those of existing studies. Only one study has evaluated a comparable group of patients; Bernbaum *et al*[5] pointed out the importance of education that facilitates problem-solving skills and supports patients in dealing with emotional issues.

The theme: *In collaboration with others allow space for innovation and self-realisation* concluded the main result. Hence, it is important, as suggested by the participants, to make local politicians aware of the importance with continuously nurse-co-ordinated educational programme.

Acknowledgements:
This study was supported by The Vårdal Foundation for Health Care Sciences and Allergy Research, Sweden, and The Swedish Diabetes Federation, Sweden. We thank FEND for supporting diabetes nursing research at Uppsala University.

Conflict of interest:
None

References

1. Bernbaum M, Albert S. Referring patients with diabetes and vision loss for rehabilitation. *Diabetes Care* 1996; **19**: 175–176.
2. Upton L, Bush A. Stress, coping, and adjustment of adventitiously blind male veterans with and without diabetes. *J Vis Impar Blind* 1998; **92**: 56–66.
3. Williams A. A focus group study of accessibility and related psychosocial issues in Diabetes education for people with visual impairment. *Diabetes Educ* 2003; **28**: 999–1008.
4. Cox D, Kiernan B, Schroeder D, *et al.* Psychosocial sequelae of visual loss in diabetes. *Diabetes Educ* 1998; **24**: 481–484.
5. Bernbaum M, Wittry S, Stich *et al.* Effectiveness of a diabetes education program adapted for people with vision impairment. *Diabetes Care* 2000; **23**: 1430–1431.
6. Anderson R, Funnell M, Butler P, *et al.* Patient empowerment-results of a randomized controlled trial. *Diabetes Care* 1995; **18**: 943949.
7. Wikblad K, Leksell J, Smide B. 'I'm the Boss': testing the feasibility of an evidence-based patient education programme using problem-based learning. *European Diabetes Nursing* 2004; **1**: 13–17.
8. Leksell J, Funnell M, Sandberg G, *et al.* Psychometric properties of the Swedish Diabetes Empowerment Scale. (In progress)
9. Graneheim U, Lundman B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today* 2004; **24**: 105–112.
10. Coyne K, Margolis M, Kennedy-Martin T, *et al.* The impact of diabetic retinopathy: perspectives from patient focus group. *Family Practice* 2004; **21**: 447–453.
11. Leksell J, Sandberg G, Wikblad K. Self-perceived health and self-care among diabetic subject with defective vision. A comparison between subjects with threat of blindness and blind subjects. *J Diabetes Complications* 2005; **19**: 54–59.
12. Skinner TC. Psychological barriers. *Eur J Endocrinol* 2004; **151**: T13–T17.
13. Glasgow R, Toobert D, Gillete C. Psychosocial barriers to diabetes self-management and quality of life. *Diabetes Spectrum* 2001; **14**: 33–41.
14. Sigurdardottir A. Self-care in diabetes model of factors affecting self-care. *J Clin Nurs* 2005; **14**: 301–314.
15. Glasgow R, Fisher E, Anderson B *et al.* Behavioural science in diabetes. *Diabetes Care* 1999; **22**: 832–843.
16. Lazare A. Shame and humiliation in the medical encounter. *Arch Intern Med* 1987; **147**: 1653–1658.
17. Perry C, Rosenfeld A. Learning through connections with others': women's cardiac symptoms. *Patient Educ Couns* 2005; **57**: 143–146.