# Diabetes education through adult learning: The Basic Education for Newly Diagnosed Type 2 Diabetes Mellitus study

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### **Article points**

- The aim of this study was to assess the effects of a patient education programme on quality of life (QOL) and self-management behaviours in people with type 2 diabetes.
- 2. Participants were assessed with four validated QOL questionnaires, and a subgroup also underwent semi-structured interviews to assess the qualitative effects.
- 3. The education programme improved anxiety and diabetes distress scores, as well as well as diabetes self-management and overall QOL. The interviews confirmed and enriched these data.

### **Key words**

- Patient education
- Quality of life
- Type 2 diabetes

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Sarah O'Brien, St Helens Clinical Commissioning Group; Jan Cardwell, St Helens & Knowsley Teaching Hospitals NHS Trust; Sunil Nair, Countess of Chester NHS Foundation trust; Kevin Hardy, St Helens & Knowsley Teaching Hospitals NHS Trust Patient education is acknowledged to be the cornerstone of effective self-management in people with chronic conditions such as diabetes. While the effects of patient education in terms of biophysical endpoints such as HbA<sub>Ic</sub> are well studied, its effects on quality of life (QOL) and other non-biophysical outcomes are less certain. In the BEND2 (Basic Education for Newly Diagnosed Type 2 Diabetes Mellitus) study, the effects of a structured patient education programme on QOL and diabetes self-management were evaluated using a number of validated questionnaires. Semi-structured interviews were also employed to provide qualitative data to add depth to the quantitative results.

here is increasing interest in understanding self-management interventions for people with chronic conditions and an acceptance of their beneficial effect (Schwappach et al, 2014). Patient education is acknowledged to be the cornerstone of effective diabetes selfmanagement (Department of Health, 2005; Diabetes International Federation, Mensing et al, 2006; Inzucchi et al, 2012). The literature on patient education in diabetes is dominated by randomised controlled trials with biophysical endpoints (Norris et al, 2002; Ellis et al, 2004). The DESMOND (Diabetes Education and Self Management for Ongoing and Newly Diagnosed) study, the largest evaluation of a structured educational programme in type 2 diabetes, showed improvements in weight loss, smoking cessation, quality of life (QOL) and beliefs about illness, but no significant improvement in HbA<sub>1c</sub>, 12 months after treatment initiation (Davies et al, 2008).

Non-biophysical measures are less well studied, but are relevant to current national educational goals (NICE, 2003) and patient

self-management. We have developed and implemented a patient education programme based on a social constructivist model of learning (Vygotski, 1962), in which participants actively work together to jointly "construct" new understanding from existing knowledge and new experience: Diabetes Education through Adult Learning (DEAL). This programme consists of a suite of complementary educational opportunities that collectively meet the diabetes educational needs of a district population. Basic Education for Newly Diagnosed People with Type 2 Diabetes Mellitus (BEND2) is one of the main programmes within DEAL, accounting for 80-90% of the scheme's diabetes education provision. Learning in BEND2 is facilitated by an appropriately trained multidisciplinary team working with small groups of people with type 2 diabetes, typically 10-12 people over four weekly, 3-hour sessions. The educational programme includes techniques to promote active learning, engagement in the process of learning and relating programme content to personal experience.

The aim of the present study was to assess the early impact of the BEND2 programme on QOL and diabetes self-management in people with type 2 diabetes. We used a combination of mutually complementary instruments to allow a broad picture of QOL, diabetes-associated distress and diabetes self-management to be built up for each individual. Assessment of patient education in chronic diseases is richer when, in addition to employing rigorous research designs to explore the quantitative effects of the intervention, it includes qualitative exploration of the participants' experience (Cooper et al, 2001).

### **Participants and methods**

The study participants comprised people with type 2 diabetes who were willing and able to participate in small-group education. Most were newly diagnosed, but some people with a longer duration of diabetes who had never had formal, structured education were enrolled. All were of white ethnicity.

This was a single-centre, prospective, non-randomised study employing a mixed-methods approach, with validated questionnaires for quantitative assessment and semi-structured interviews for qualitative assessment. The study was approved by the local Research Ethics Council, and all subjects gave written informed consent before undertaking study activities.

Each participant completed the four QOL questionnaires (listed below) in a quiet room in the diabetes centre, before, and 2 weeks after, completion of the 4-week education programme. We used four well-validated questionnaires which had clear, standardised scoring and reporting systems and normative data for comparison. The questionnaires were stable and could be used to evaluate change over time and have previously been used in large patient education trials (Davies et al, 2008). Participants spent approximately 20 minutes completing the four questionnaires.

### **QOL** questionnaires

Consistent with the DESMOND study, the following four questionnaires were used.

### World Health Organization QOL Inventoryshort form (WHOQOL-BREF)

This is a validated instrument used to assess individuals' perceptions of their position in life in the context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns (WHO, 1995). It yields a multidimensional profile of scores across domains and sub-domains (facets) of QOL, and it can be used to assess variation in QOL across different cultures, compare subgroups within the same culture and measure change over time in response to changes in life circumstances. It measures QOL in four domains: physical, psychological, social relations and environment. In total, it has 26 questions scored 1-5, with higher scores indicating increased QOL.

# **Summary of Diabetes Self-Care Activities** (SDSCA)

This is a brief, self-report questionnaire of diabetes self-management that includes items on general diet, specific diet, exercise, blood glucose monitoring, foot care and smoking. It has 11 questions, with higher score indicating a higher number of positive self-care activities. It has previously been evaluated and validated, and has reasonable internal and test-retest reliability, validity and sensitivity to change (Toobert et al, 2000).

## **Hospital Anxiety and Depression Scale** (HADS)

This is an instrument used to detect the presence and severity of mild degrees of mood disorder, anxiety and depression, which has been extensively evaluated and has reasonable reliability (Zigmond and Snaith, 1983; Bjelland et al, 2002). The scale consists of 14 items, each scored 0–3, and is sensitive to mild disturbances. Higher total scores indicate greater severity of anxiety or depression. Scores of 8–10 indicate possible clinical disorder and scores of 11–21 indicate probable clinical disorder.

### **Problem Areas In Diabetes (PAID)**

This tool is a measure of emotional distress that was developed by Polonsky et al (1995). It

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Table 1. Changes in QOL indicators from baseline to 6 weeks.			
	Baseline (median; IQR)	6 weeks (median; IQR)	Change in mean (95% confidence interval)
World Health Organization QOL Inventory-short form			
Physical domain	26 (19–29)	27 (22–30)	1.46 (0.4–2.4)*
Psychological domain	23 (18–25)	24 (20–26)	1.02 (0.03–2.0)*
Environmental domain	12 (10–14)	12 (10–13)	0.23 (-0.2 to 0.7)
Social domain	32 (28–36)	32 (29–36)	-4.04 (-14.3 to 6.2)
Summary of Diabetes Self-Care Activities			
General diet	5 (4–7)	6 (5–7)	0.69 (0.53–1.33)*
Specific diet	4 (3–5)	4 (3–5)	0.12 (-0.36 to 0.6)
Exercise	3 (1–4)	5 (1–5)	0.43 (-0.11 to 0.96)
Blood glucose testing	0 (0-3)	3 (2–5)	1.95 (0.13–1.48)*
Foot care	2 (0-5)	3 (1–6)	0.81 (0.13–1.48)*
Hospital Anxiety and Depression Scale			
Anxiety	10 (7–12)	8 (7–10)	-1.13 (-1.85 to -0.91)*
Depression	12.5 (11–13)	12 (11–13)	-0.04 (-0.50 to 0.41)
Problem Areas in Diabetes			
Diabetes-related distress	13 (7–27)	5 (1–15)	-8.91 (-11.9 to -5.8)*
Exercise concerns	8.5 (5–22)	3 (1–10)	-6.15 (-8.3 to -3.9)*
Treatment-related problems	2 (0-4)	0 (0-2)	-1.02 (-1.6 to -0.4)*
Food-related problems	2 (1–6)	1 (0-3)	-1.96 (-3.1 to -0.73)*
Social concerns	0 (0–2)	0 (0-0)	-0.36 (-0.79 to 0.06)
*P<0.05.			

consists of a 20-item questionnaire, with scores ranging from 0 to 4 for each item. High scores indicate more severe problems. The total score can be used as a measure of diabetes distress, but factor analysis has identified four factors that are likely to be clinically relevant: diabetes-related emotional problems, treatment-related problems, food-related problems and social

### **Interviews**

support-related problems.

IQR: interquartile range; QOL: quality of life.

Semi-structured interviews were included to add richness and texture through individuals'

observations about their personal experience. The semi-structured design allowed themes consistent with the questionnaires to be explored in more detail. As per protocol, five participants randomly selected by a nurse who was not involved with the programme were invited to take part in more detailed, video-recorded and transcribed interviews to supplement the quantitative data with a richer narrative in the participants' own words.

### Statistical analysis

Data were analysed in SPSS version 16.0 (SPSS Inc, Chicago, IL, USA). Normally distributed data are reported as means and non-normally distributed data as medians. All questionnaire scores were tested for normality using the Kolmogorov–Smirnov and Shapiro–Wilk tests. The majority of scores for each questionnaire were non-normally distributed; therefore, paired data were tested for significance using the paired, non-parametric Wilcoxon signed-rank test. A *P* value of <0.05 was taken to be statistically significant.

### **Results**

A total of 61 people with type 2 diabetes were enrolled in the study. Of these, 14 (23%) failed to complete the whole programme and, as per the study protocol, had their data censored. Of the 47 who completed the study, 62% were male, the mean age was 57 years, the median diabetes duration 0 months, the median weight 95 kg and the median BMI 33 kg/m<sup>2</sup>. At baseline, the mean HbA<sub>10</sub> was 54 mmol/mol (7.1%), the mean blood pressure 140/76 mmHg and the mean LDL-cholesterol level 2.6 mmol/L; the average educational attainment was "high school" level. Regarding marital status, 15% of participants were single, 66% were married or living as married, 5% were separated or divorced and 14% were widowed.

The changes in QOL indicators from baseline to 6 weeks are summarised in *Table 1*. The BEND2 programme resulted in improvements in WHOQOL-BREF physical (mean change, 1.46; P=0.007) and psychological (1.02; P=0.03) domain scores; reductions in HADS anxiety scores (-1.13, P=0.004), PAID total

diabetes distress (-8.91; P<0.001), treatment distress (-0.02; P=0.004), exercise concern (-6.15; P<0.001) and food stress (-1.96; P=0.001) scores; and improvements in SDSCA general diet (0.69; P=0.03), blood glucose testing (1.95; P<0.001) and foot care (0.81; P=0.02) behaviours.

The semi-structured interviews were analysed by two individuals, and observations on the themes that emerged were strikingly concordant. Consistent themes among the participants are described in *Box 1*.

### **Discussion**

The principal findings of this pragmatic study are that people with type 2 diabetes are frightened and anxious at diagnosis, and that ignorance and distress lead to a sense of helplessness. On completion of BEND2, anxiety, depression and diabetes-related distress scores were greatly reduced, participants felt reassured and more confident, and self-management skills and QOL were significantly improved.

The people enrolled in the BEND2 programme were typical of the local type 2 diabetes population in terms of age, gender, biophysical profile, employment status, co-morbidities and complications. Recruitment in the study was limited to adults who were able to complete the programme. In a related unpublished study, we examined the impact of telephone reminders on course attendance. Perhaps surprisingly, a telephone reminder before the first visit (*n*=86) made no difference to initial or subsequent non-attendance rates when compared with a group (*n*=127) that was not telephoned (29% vs 27%).

In the present study, the average age, gender distribution and biophysical measures were similar to those observed in DESMOND (Davies et al, 2008). Thus, overall, the study subjects were representative of those who need type 2 diabetes education in the UK, and these results should be transferable to the population as a whole.

The mixed methodology, using questionnaires that are relatively quick and cost-effective, complemented by semi-structured interviews

### Box 1. Themes observed in semi-structured interviews

- Diabetes diagnosis is associated with fear, anxiety and a sense of helplessness.
- Basic Education for Newly Diagnosed Type 2 Diabetes Mellitus (BEND2) made participants feel better and was perceived to be useful.
- Further top-up education would be useful.
- Initial fears of complications were relieved and participants felt reassured by BEND2.
- A change of approach and attitude occurred as a result of BEND2.
- Group members felt they had a lot to learn from each other and were comforted by the knowledge that there were other people in the same boat.
- There was praise for the facilitators, and participants were reassured by having a contact number after discharge.
- There was initial confusion about healthy eating, but participants were relieved when told that it was not essential to cut out all nice foods.
- There was a sense of being in control of diabetes management after the course.
- Participants gained confidence in asking for and interpreting tests and checks, and in offering advice to others.
- Participants believed that everyone should undergo the course at diagnosis.
- One person with longer-standing diabetes felt he did not gain much in terms of self-management (because he already knew it).
- The course was relaxed and good fun.

and data triangulation, added depth and richness of personal experience. For example, a surprising proportion of participants had elevated anxiety and depression scores on the HADS, but detailed interviews were entirely consistent with this finding and deepened our understanding of why participants felt this way and what must done to address this problem. In the first instance, we think clinicians should look for persistence of abnormal scores/feelings in the months beyond diagnosis, particularly since anxiety and depression both improved with education. If these symptoms are persistent and triangulated by other assessments of anxiety and depression, then specific psychological intervention, such as cognitive behavioural therapy or even pharmacotherapy, might be indicated.

The questionnaires employed in this study have been well validated in people with diabetes and provide a valid and reliable assessment of QOL (Welch et al, 1997; Toobert et al, 2000; Bjelland et al, 2002; Rose et al, 2002). It can be difficult, however, to understand the clinical relevance of a statistically significant improvement in test performance. The semi-structured interviews provide much

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richer information with which to understand the clinical meaning of changes in test scores. In this study, the interviews lent strong support to the interpretation that not only were many of the improvements in QOL and performance statistically significant, but they were also clinically significant, adding real value to people's lives. Any successful education programme for people with chronic conditions, such as diabetes, will help the participants take control of managing their condition and limit their need for contact with healthcare professionals (Adams et al, 1997). Interview data from this study very clearly demonstrate that the participants made a transition towards increased personal responsibility for their diabetes; indeed, several interviewees discussed how they then went on to help others with diabetes manage the condition.

The weakness of this study is that it was conducted in a single centre and had a short follow-up. Further research is needed to establish whether these beneficial effects are long-lasting and whether top-up education or ongoing support will further improve QOL. Crucially, we must also examine whether improved self-care behaviour translates into long-term improvements in biophysical surrogates, such as HbA<sub>1c</sub>, and better health outcomes. Nevertheless, improved QOL and reduced anxiety, depression and distress are pivotal to health and well-being, and are worthwhile outcomes in their own right.

### **Conclusion**

This study has demonstrated the positive impact of a structured education programme for people with newly diagnosed type 2 diabetes on QOL, anxiety and depression. Moreover, this programme was successfully implemented into routine diabetes care and offered to all newly diagnosed patients who were referred to the local specialist team. However, as with many existing education programmes, more work is needed to evaluate the sustainability and long-term impact of such programmes.

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