Living with Diabetes: an educational model of care for new onset diabetes

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Abstract
The first year following diagnosis is a critical time for those newly diagnosed with type 1 diabetes and is likely to influence long-term glycaemic control. This paper describes a group education programme, Living with Diabetes (LwD), and reports the outcome data at one year and three years after diagnosis. HbA1c was compared with outcomes from the cohort diagnosed during the four years prior to the inception of LwD. We have demonstrated that, in terms of HbA1c, the programme achieved outcomes similar to the traditional model with similar staff resources. The LwD pathway required an additional 2.9 hours per patient but HbA1c values were consistently lower in those who attended all sessions. The data suggest the need for more concerted attention to engage patients in an ongoing care pathway during the early years following diagnosis. An evaluation of the programme suggested that patients valued the relaxed non-hierarchical nature of the group and the opportunity to share with and ask questions of their peers. Copyright © 2013 John Wiley & Sons.

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Key words
type 1 diabetes; newly diagnosed; education; multidisciplinary

Introduction
The diagnosis of type 1 diabetes is a significant life event. For some it is the confirmation of suspicions based on symptoms; for many it is a relief that the symptoms can be explained and managed, while for others it is a devastating shock that is extremely difficult to accept and come to terms with. Whatever the emotional reaction, the practical necessities of this diagnosis require integrating into daily routines: self-care activities of blood glucose monitoring, injecting insulin and monitoring diet. The way people are given their diagnosis and information about the condition can vary considerably. However, the approach is important as it can influence the patient’s attitude towards their condition and subsequent self-management.

Focus groups in a local study identified the period of time around diagnosis as the most important. The groups reported a significant degree of psychological distress and suggested that initially more support is required together with greater flexibility for visiting health care professionals. Continuous education was seen as an essential part of diabetes care and necessary to help improve self-management skills. Some patients reported increasing frustrations as the ‘novelty’ of the diagnosis wore off and glycaemic control became more difficult. A small group of people who did not improve their glycaemic control, following both an intensive insulin training programme and a motivational interviewing intervention, described difficulties which may have originated at the time of diagnosis.1

Prior to 2004, the newly-diagnosed adult at our centre was offered multiple appointments for the first few weeks with different members of the multidisciplinary team and then followed up in routine secondary care clinics. The support varied for each patient, and tended to be unstructured and with no formal education objectives once glucose control had stabilised. This meant that patients were left on their own to manage issues such as hypoglycaemia, exercise and other situations, which increased their psychological burden and contributed to deteriorating glycaemic control in the years following diagnosis. This observation together with the feedback from the focus groups was consistent with the findings of the Listening Project, commissioned by Diabetes UK in 2006;2 and highlighted the need to improve the service available to patients at the time of diagnosis. With the renewed focus in recent years on carbohydrate counting and flexible insulin...
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dosing, we felt it was important that patients learn about these in a structured manner from the time of diagnosis, rather than having to wait until they attend an intensive structured education programme. (An intensive programme is often not appropriate while patients are in a honeymoon period).

Living with Diabetes (LwD) was devised as a group education programme based on Bandura’s social learning theory and cognitive reframing methods. Social learning theory suggests that individuals can learn new behaviours through observing the behaviour of others. Cognitive reframing is a teaching method that offers alternative perceptions to the person with diabetes which may be more advantageous to their self-management skills. The programme consisted of multidisciplinary group education sessions, delivered once every three months, so that for the 12 months following diagnosis patients attended four sessions which replaced clinic visits. The aim was to facilitate consistent and reliable self-management skills.

This paper describes the care pathway and curriculum for Living with Diabetes (LwD) and reports outcome data at one year and three years after diagnosis. The HbA1c data were compared with outcomes from the cohort diagnosed during the four years prior to the inception of LwD (pre-LwD group).

Method

Living with Diabetes care pathway

Type 1 diabetes patients are seen on the day of diagnosis by a diabetes specialist nurse (DSN) to commence multiple daily injections of insulin and blood glucose monitoring. During the next four weeks, the DSN and diabetes dietician assess progress and introduce the concepts of carbohydrate counting and flexible insulin dosing, and all patients have a clinic consultation with a consultant within six weeks. Patients are invited to attend the next LwD session scheduled after diagnosis which can be anything from the following week to three months later.

Patients attend four meetings at three-monthly intervals. HbA1c is measured prior to or at each session, and blood pressure and lipids are monitored if they were abnormal at the first clinic visit. Patients complete the Hospital Anxiety and Depression Scale (HADS) and the Problem Areas in Diabetes Scale (PAIDS) at each visit. After the first year following diagnosis, patients are followed up in routine clinics every four to six months. They are encouraged to attend the BERTIE intense education programme during the second year following diagnosis.

Structure of sessions

The aims of the sessions are to support the development of self-management and problem-solving skills and to offer psychological and peer support. Rolling group sessions are held every three months and are attended by a DSN, dietician and clinical psychologist with input from a consultant physician. All patients diagnosed with type 1 diabetes in the previous 12 months are invited to each of the four groups during the first year of diagnosis. Refreshments are available and the session lasts approximately 2 hours.

Each session is facilitated by a different team member and begins with small group discussions on a particular theme, followed by feedback of patient experiences and questions (see Figure 1). The topics are designed to facilitate discussion with trigger questions relevant to the theme, but frequently diversify to meet the specific needs and experiences of participants. Flip charts, food models, ‘hypo’ treatments and other supplementary materials are used as required. After the group meeting, there is an opportunity for patients to discuss specific issues on an individual basis, with any of the professionals present.

Each session is followed by a multidisciplinary team meeting at which each patient is discussed, including those who did not attend. Further individual appointments are made according to patient need.

Measures and data analysis

The primary outcome measures were changes in HbA1c at one and three years after diagnosis (in both the LwD and pre-LwD groups) and psychological questionnaire data in the LwD group; the association between the number of LwD sessions attended and HbA1c was monitored, as was the mean staff time per patient. PAIDS was designed to assess diabetes-specific emotional problems. The questionnaire consists of 20 items rated on a 5-point Likert scale ranging from 0 (no problem) to 4 (serious problem). The reported scores range from 0–80. A threshold of ≥33 has been suggested to be an indicator of significant diabetes distress and clinical depression. HADS is a 21-item, self-report questionnaire to assess symptoms of anxiety and depression. It was designed to identify cases of anxiety and depression in patients with
non-psychiatric illnesses and scores are categorised as mild (8–10), moderate (11–14), and severe (15–21). HbA1c was measured by IFCC standardised assay and demographic data were obtained from the clinic database. All patient contacts were recorded on the clinic database and used to compare the staff time requirement of the LwD programme compared with the previous system. A patient satisfaction survey was posted in 2008 to all patients who had attended Living with Diabetes sessions from 2004–2008.

Data were analysed using Predictive Analytic Soft Ware (PASW) Version 18. For significance tests a two-sided 5% level was used. Statistical analyses were performed using independent t-tests to analyse the differences between various time points.

**Results**

Eighty-seven adults were newly diagnosed with type 1 diabetes during the four-year evaluation period. Four were subsequently excluded because they were found to have medication-induced diabetes, type 2 diabetes, secondary diabetes or to be pregnant. Analysis was conducted on 66 people (41 male) with newly-diagnosed type 1 diabetes who participated in the LwD sessions. Their mean (SD) age was 37.5 (14.0) years. Of the 17 people who did not participate in the programme, three moved from the area and 14 attended individual outpatient clinics. There were 74 (42 male) patients in the pre-LwD group (mean age 39.8 [15.4] years).

**HbA1c comparisons between pre-LwD and LwD**

There was no difference between the baseline mean HbA1c for each group, and the mean HbA1c was similar in both groups at one and three years’ follow up (Table 1).

**Attendance**

The intensity of input was determined by the number of LwD sessions attended. Table 2 shows how lower HbA1c was associated with a greater number of sessions attended.

Figure 2 shows the change in HbA1c from one to three years after diagnosis, according to the number of sessions attended. It can be seen that those who attended individual outpatient clinics in preference to LwD (n=14) had consistently higher HbA1c during the three-year follow up.

**Psychological questionnaires (Living with Diabetes)**

PAID scores reduced during the first year from mean (SD) 14.9 (11.0) to 11.0 (7.5). None of the available sample scored above 33 at one year; however, four patients who had scored >33 at diagnosis did not complete questionnaires at one-year follow up. There were insufficient data to make a meaningful comparison between the change in scores at diagnosis and at one year.

Mean symptom scores for anxiety and depression (HADS) at diagnosis were below the range indicating clinical relevance and showed a reducing trend at one year (anxiety 6.7 [3.8], 4.9 [3.9], depression 3.2 [3.0], 2.4 [2.7]).
Staff time per patient
The total contact time before the introduction of Living with Diabetes was 5.4 hours per patient. The standard LwD programme, together with additional individual appointments in the weeks following diagnosis and as needed between group sessions, required 6.3 hours per patient. The LwD pathway therefore takes an additional 2.9 hours per patient, for an average year during which we have 13 newly diagnosed, which equates to 38 hours per year (Table 3).

In addition, eight LwD patients spent a mean 5.8 hours (range 1–12) individually with the clinical psychologist. Each had pre-existing mental health problems which adversely affected their ability to manage their diabetes, and which were identified by having clinical psychologist input into the programme. Their mean HbA1c was 63mmol/mol (range 48–84) at one year and 69mmol/mol (range 54–91) at three years (DCCT 7.9% [6.5–9.8] and 8.5% [7.1–10.5], respectively). It is unlikely that the need for psychological intervention would have been identified so rapidly under the previous system of care.

Patient evaluation
A questionnaire was posted to all patients who attended the LwD programme during the period under review. There is potential bias in terms of the accuracy of recall for those who attended LwD at its inception, while those who attended latterly may have been more likely to return the questionnaire. Non-response to postal questionnaires is a familiar problem and, although there was no incentive to enhance the returns, the response rate of >50% (n=23) was within the accepted range. The majority found the programme useful or very useful (20), felt the sessions were sensitive to their personal needs, fears and anxieties (21), and found it useful to share experiences with peers (19). Twenty-one reported that they felt confident or very confident in understanding blood glucose levels, how insulin works, adjusting insulin doses according to carbohydrate intake and high glucose levels, and in understanding the need for regular medical checks including blood pressure etc. Eighteen felt confident in coping with high glucose levels during illness and 19 in managing exercise.

Discussion
Prior to Living with Diabetes, patients were seen several times following diagnosis until their glucose control stabilised, and were then left to their own devices to manage as best they could until their next clinic visit which may have been several months away. There was no structure in place to ensure patients fully understood important concepts of self-management, and whether they returned to see a DSN or diettitian was largely dependent upon whether they experienced any problems. To some extent, further input was therefore crisis management.

Living with Diabetes enables all patients to be seen at three-monthly intervals following the diagnosis of type 1 diabetes, with the emphasis on an educational model of care, which develops patients’ self-management skills by problem solving and learning from peers. We have demonstrated that, in terms of HbA1c, it achieved outcomes similar to the traditional model with only a modest increase in staff time per patient (2.9 hours). This was despite several patients not attending all four sessions. Those who did attend the full programme appeared to fare even better. Reasons given for non-attendance included holidays, illness, and difficulty taking time off work; however, these were not recorded. Those who attended all four sessions did not report higher levels of diabetes distress or higher anxiety symptom scores compared with less frequent attendees.

The satisfaction questionnaire suggested that the LwD programme was well liked by participants with new-onset type 1 diabetes. Patients valued the relaxed, non-hierarchical nature of the group and the opportunity to share with and ask questions of their peers. The vast majority of respondents felt confident in the basic self-management skills covered by the programme; however, there was no objective assessment to confirm this.

While there was a reduction in the mean PAIDS total score and HADS symptom scores, the means for all variables were in the non-clinical range from diagnosis. It is widely reported in the literature, and also described in our focus groups, that diagnosis is a particularly difficult time for patients and is associated with high levels of distress. The absence of significant levels of emotional distress in the LwD cohort might indicate that the supportive and educational nature of the programme reduces the trauma and emotional distress associated with adjusting to the life-changing diagnosis of diabetes.

The group format of Living with Diabetes is an efficient way to deliver care, while providing more direct contact time for each patient. The latter meant that the specific psychological needs of
vulnerable patients were responded to in the context of their diabetes care.

The greater HbA1c improvement in those who attended the full programme suggests the need to highlight the importance of attending all sessions in order to maximise the learning opportunities.

An unanticipated benefit of the programme has been that patients have had the confidence to make significant adjustments to their insulin themselves according to need. Not only did they adjust their insulin to carbohydrate ratios but, in a number of cases, patients stopped taking bolus insulin for one or two meals during the day, with no adverse effect on their overall control. Their low insulin requirements either resulted from being in a honeymoon period or from increased physical activity – for example, working as a labourer. One could postulate that without the knowledge and confidence to make these changes, they would have been at risk from recurrent hypoglycaemia with its attendant physical and psychological risks.

The rise in HbA1c after the first year is not unexpected as many will have come out of the honeymoon period during the second year. The data suggest the need for more concerted attention to engage patients in an ongoing care pathway during the early years following diagnosis.

Declaration of interests
There are no conflicts of interest declared.

References