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School of Medicine

Addressing the Educational and Psychosocial Issues in Type 1 Diabetes

By

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Correction Sheet

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ABSTRACT

FACULTY OF MEDICINE, HEALTH & LIFE SCIENCES
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ADDRESSING THE PSYCHOSOCIAL AND EDUCATIONAL ISSUES IN TYPE 1 DIABETES

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People with type 1 diabetes require good self-management skills in order to achieve good levels of diabetes control. Self-management skills can be onerous and can cause significant disruption to people's lives. Improving knowledge through structured education programmes can help to improve self-management skills. However psychosocial barriers can prevent some patients developing the necessary skills. The aim of this work was to use qualitative and quantitative analysis to identify some of these barriers so that more appropriate diabetes services can be developed.

Focus groups were held to assess patients' views on clinic visits. The results suggested that the time at diagnosis was the most difficult and required better support and so the 'Living with Diabetes' programme was developed to improve support for individuals with newly-diagnosed type 1 diabetes. The programme resulted in significant improvements in glycaemic control and qualitative analysis suggested that patients felt in control of their diabetes and had developed good problem-solving abilities. Analysis of the Bournemouth Intensive Education programme demonstrated that this programme can help individuals to improve their HbA1c by 0.5% and maintain this improvement over four years. Further work with individuals who did not improve their glycaemic control with intensive education suggested that 'readiness to change' was an important factor which needs more assessment. Finally a brief motivational interviewing programme was designed for these individuals. Glycaemic control did not improve after the programme but qualitative analysis suggested some of these patients lacked confidence and had poor coping skills which may have stemmed from poor care at diagnosis. The 'Living with Diabetes' programme may help to prevent some of these difficulties and further analysis of this programme is needed to assess the long term benefits.

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1 Introduction

In 1989 the St Vincent declaration developed a series of targets to improve the quality of life for people with type 1 diabetes.[1] The declaration recognized that active partnerships with treatment teams were needed to encourage effective self-management and independence in people with type 1 diabetes. They recommended that comprehensive programmes teaching diabetes management should be provided for people with diabetes, their families and health care professionals. They also advocated that effective measures should be implemented to reduce the rates of blindness due to diabetic retinopathy, end-stage renal failure, cardiovascular mortality and limb amputations as well as improving the outcomes in pregnancy for women with diabetes. The results from the Diabetes Control and Complications Trial also emphasised the need for good glycaemic control suggesting that an HbA1c of less than 7% could delay the onset and slow the progression of microvascular and macrovascular complications.[2;3] Despite the improvements in insulin regimes and insulin delivery the targets from the St Vincent declaration have not yet been achieved and about 25% of people with type 1 diabetes have poor glycaemic control although this figure may be higher in adolescent patients.[4;5] The reasons for this are complex and may in part be due to physiological barriers such as inappropriate insulin regimes. However, psychosocial barriers can also develop from the impact of the diagnosis or from the stress of living with diabetes and significantly affect the individuals' self-management skills and hence glycaemic control. Type 1 diabetes requires higher levels of self-management compared with many other chronic diseases.[6] The self-management skills required are onerous; they include giving insulin injections, monitoring blood glucose levels in addition to balancing diet, exercise and weight. Individuals with type 1 diabetes need to learn how to adapt their lifestyle in order to achieve good levels of diabetes control with minimal disruption to their daily lives.[7] However, disruption is sometimes inevitable and patients often feel a loss of freedom which is compounded by dietary restrictions and hypoglycaemia. They may also develop concerns relating to the risks of complications.[8] Education plays an important part in improving a person's knowledge about diabetes but improvements in knowledge do not necessarily result in changes in self-care behaviour and good glycaemic control. Hence while structured education programmes are essential it is important to recognise any psychosocial barriers to self-management. Identification of these barriers may help the development of more appropriate diabetes services, specifically education programmes, which facilitate improvements in self-management skills.

1.1. Education Programmes

Patients with type 1 diabetes need to acquire the knowledge and skills necessary to adapt to life with a chronic disease.[9] However the Audit Commission Report, published in 2000, found that only one third of hospital diabetes centres offered a structured patient education programme and only two thirds of patients had access to an education programme in the previous 12 months.[10] Furthermore many of the programmes available were for people with type 2 diabetes. The Diabetes UK Report in 2002 found that patient education was disorganised and often seen as an optional service.[11] At that time education programmes were not delivered efficiently or consistently and were commonly only for newly-diagnosed patients. A review of diabetes educational interventions undertaken in 2001 suggested that 80% of programmes used a didactic approach and goals were often dictated by the health care provider (33%).[12] There was also little recognition of the impact of psychological distress on patients' glycaemic control or assessment of psychological distress. The National Institute for Clinical Excellence(NICE) guidelines[13] and National Service Framework for Diabetes[14] have recognised the need for structured education and have stated that education programmes should be available to all people with diabetes at the time of diagnosis and then as required, and this has led to a drive to improve the delivery and structure of education programmes in the UK.

The aim of education has evolved from encouraging patients to adhere to treatment to providing information and support for individuals to make informed decisions about their diabetes management.[15] Standard 3 in the National Service Framework, has emphasised that the people with diabetes should 'receive a service which encourages partnership in decision-making' and support patients in self-managing their diabetes. Therefore diabetes educators should not rely on a didactic approach but try to empower patients with diabetes.[16] There are no ‘universally effective’ education programmes. Insights gained from other studies can be used to develop programmes that are suitable for specific centres taking into account the culture and location where the training is delivered.[17] Acquisition of knowledge alone will not necessarily result in sustained behaviour change although it remains an important part of diabetes education.[18] Training programmes incorporating behavioural and affective components are generally more effective than those which are didactic or knowledge- and skills-based[19] particularly if they are designed specifically to suit the community in which they are delivered. Teams which incorporate patient-centred education with goal-setting into general care are often the most effective.[20]

1.1.1 Patient Education in Düsseldorf

The DCCT was able to demonstrate the benefits of intensive insulin therapy.[2] However, the three-fold increase in hypoglycaemia and high staff to patient ratios prevented the integration of this approach into general diabetes practice.[21] Furthermore, less than 10% of the intensively treated group managed to maintain the glycaemic goals on a long-term basis.[9] This suggests that the improved control was dependent on frequent health care professional contact rather than patient self-management. A group in Düsseldorf, Germany has been developing and improving education programmes for type 1 diabetes for over two decades. Evaluation of the Düsseldorf programme demonstrated that intensive insulin therapy, combined with diabetes education, resulted in a reduction in HbA1c of 1.5% with no increase in severe hypoglycaemia or weight gain despite the liberalisation of diet.[22] This programme has been implemented throughout Germany, consistently showing benefits in glycaemic control.[23;24] This model has also been used in other European countries with similar effects[25] and many education programmes in the UK have been based on the Düsseldorf programme.[22] Studies have been carried out by the Düsseldorf group, looking at the impact of the programme on hypoglycaemia and diabetes knowledge.[26] They evaluated the effects of their five day programme and found that patients with less knowledge had higher HbA1c levels and a higher incidence of hypoglycaemia. Certain gaps in diabetes knowledge with regard to the effects of physical activity, nutrition and long-term complications were identified in patients with severe hypoglycaemia. However the HbA1c level was most closely associated with diabetes knowledge and not influenced by educational level or any other factors such as insulin dosage, age, diabetes duration or BMI. It was felt that other factors, such as psychosocial aspects, may influence diabetes knowledge and subsequent self-management skills and glycaemic control. Bott et al also looked at the predictors of glycaemic control following participation in a structured education programme in 697 patients with type 1 diabetes. The most consistent predictor in all regression analyses was found to be smoking. Smoking was associated with lower socioeconomic and education status and smokers may also have different health beliefs and coping strategies. These factors may all have contributed to poor glycaemic control. Diabetes knowledge, perception of coping abilities, age at onset of diabetes and C-peptide levels were also important predictors of glycaemic control. However the variance in HbA1c was not fully explained by these variables and suggests that other psychosocial factors may have contributed. These psychosocial factors were not measured and need to be investigated in more detail. The education programme did not negatively impact quality of life despite the increased frequency of injections, insulin dose adjustments, blood glucose monitoring, suggesting the acceptability of this programme to people with type 1 diabetes.[27]

1.1.2 Non-responders to Patient Education

The Düsseldorf programme was initially developed to help patients with newly-diagnosed type 1 diabetes or patients who were being transferred onto a multiple daily insulin regime from conventional treatment.[28] An evaluation of the patients who were referred to the Düsseldorf centre in 2003, however, showed that fifty-one percent of these patients had already attended an intensive insulin education programme. Twenty-six percent of these patients already had good metabolic control with HbA1c levels less than 7.5% but had been referred to improve flexibility and motivation, refresh diabetes knowledge and improve levels of hypoglycaemia. The standard programme was deemed redundant for these patients and a more holistic teaching programme was developed to give participants the opportunity to discuss motivational aspects, psychosocial problems and coping strategies. The HbA1c of the eighty-three participants in this programme remained unchanged at follow-up although there was a reduction in severe hypoglycaemia. Patients improved their perceptions of self-efficacy as well as their relationship with doctors. This group of patients had longer diabetes duration in comparison with those from other studies[24;29;29] and those patients with poor control at follow-up often had motivational deficits, problems with emotional coping, and lack of social support. Subjective evaluation also suggested that these patients would have liked more individual psychosocial support. It is possible therefore, that addressing psychosocial morbidity prior to the programme may influence glycaemic control in this particular group of patients.

1.1.3. The DAFNE Programme

The Dose Adjustment for Normal Eating programme (DAFNE)[21] is based on the Düsseldorf programme. It is a five day outpatient programme, in the UK, which aims to provide patients with the skills to match insulin to their carbohydrate intake. A multi-centre randomized control study was used to test the DAFNE approach. Patients were invited to participate in this trial if they had type 1 diabetes, moderate or poor glycaemic control (HbA1c 7.5-12%) and diabetes duration of more than two years without advanced complications. This was a waiting list controlled trial with one group of patients randomized to an immediate DAFNE programme and the other to a delayed DAFNE programme six months later. The results showed a significant reduction in HbA1c from 9.4% to 8.4% at six months although the results at twelve months showed deterioration to 8.9% and therefore the overall mean change was 0.5% (95% confidence interval 0.2-0.9, p=0.001). Significant improvements were seen in quality of life as well as psychological well-being and this was sustained at one year despite an increase in the number of injections and frequency of blood glucose monitoring. The use of DAFNE in other UK centres did precipitate concern with regard to resource implications. However, it may be that developing knowledgeable, empowered patients will be cost-effective in the future as patients will need less contact with health care professionals[30] and recent analysis has suggested that that this programme could save resources for the NHS[31].

1.1.4. Bournemouth Type 1 Intensive Education Programme

The Bournemouth Type 1 Intensive Education Programme (BERTIE) for patients with type 1 diabetes started in 1999.[32] Until then, type 1 diabetes education had been unstructured and haphazard depending on the health care professionals involved. This was in contrast to the structured education programmes that had been developed in Bournemouth for people with type 2 diabetes. The BERTIE programme was originally based on the curriculum of the Düsseldorf programme,[33] but has since been adapted to become more patient-centred and goal-orientated and is open to anyone with type 1 diabetes including patients with advanced complications. The programme is run on one day a week over four consecutive weeks. The first session includes goal setting and an introduction to carbohydrate counting. Subsequent sessions cover insulin dose adjustment, information on the treatment of hypo- and hyperglycaemia and the effects of exercise and alcohol on blood glucose levels. Carbohydrate counting and insulin dose adjustment allow flexibility in diet and insulin doses and challenge the tradition that fixed insulin doses and dietary manipulation are necessary to achieve good glycaemic control. This is important as dietary restriction has been shown to have the most significant restriction on quality of life.[34] All patients are on a multiple daily insulin regime mostly with analogue insulin. The schedule allows participants to implement changes to their insulin doses and monitor the effect of the changes on their blood glucose levels during the week between sessions and receive feedback at each session. The timing of the sessions also allows the programme to be implemented without affecting the other work in the department. A meal is included with each session to encourage and support the participants with carbohydrate counting.

Fifty-eight patients participated in the programme in the first three years. 28 participants were male. The mean age of the participants was 32 (range 18-65 years) and the mean duration of diabetes 2 years (0.6-34 years). Baseline, three month and six month data was available for all participants and data for thirty-three and twenty-one patients was available at twelve and twenty-four months respectively. The baseline HbA1c fell from (mean ± SE) 8.9 ± 0.2% to 8.4 ± 0.2% at three months and this fall was maintained at six months. However there was a slight deterioration to 8.6±0.2% at twelve months but at twenty-four months glycaemic control improved to 8.3±0.5% in twenty-one participants. This programme was open to all individuals with type 1 diabetes, regardless of their HbA1c level and there were 17 participants who had good glycaemic control prior to completing the programme. The participants were therefore subdivided into two groups. Participants with an HbA1c above 8% prior to the programme, showed a fall in HbA1c from 9.6% ± 0.15% to 8.8 ± 0.2% at three months ($p<0.001$). This fall in HbA1c was maintained at one year and fell further to 8.3 ± 0.4% at two years. Participants with good glycaemic control (HbA1c<8%), prior to the programme, maintained this for six months but there was a significant rise in HbA1c of 1% at twelve months and a further deterioration at two years. This group included four participants with recent-onset diabetes and their participation in the programme may have coincided with the end of their honeymoon period.

The changes in glycaemic control also appeared to be influenced by duration of diabetes. Participants with a longer duration of diabetes and poor glycaemic control at entry, showed an initial fall in HbA1c from 9.5% at baseline to 8.7% at 6 months but control deteriorated to 9.6% at 12 months. HbA1c levels in participants with shorter disease duration fell from 9.7% at baseline to 8.2% at one year.

The Ipswich questionnaire[35] was used to assess self-management skills. The Ipswich scores rose from 135 at baseline to 151 at three months and this was maintained at twelve months. The responses to the questionnaire highlighted improvements in blood sugars in the normal range, perceived improved control, more confidence in adjusting insulin doses, more confidence in carbohydrate counting and increased knowledge about managing exercise and illness. This demonstrated that an intensive education programme could be successfully implemented in the UK without adverse effects to the clinical services or department resources.[36]

1.1.5. Evaluation of Patient Education

Patient education is defined as ‘the planned learning experience using a combination of methods such as teaching, counselling and behaviour modification techniques which influence patients' knowledge and health and illness behaviour.[37] It is the combination of these different elements that makes programme evaluation in diabetes more difficult, as it is hard to identify which element of education is responsible for the change in glycaemic control.[38] Unlike many other interventions in diabetes, there is no recent meta-analysis for diabetes educational interventions. This is largely due to the difficulty in characterising diabetes education when the literature is reviewed as well as inconsistencies in the reporting of different aspects of educational programmes.[39] The meta-analysis by Brown et al in 1990 suggested that diabetes patient education can improve patient outcomes although a significant number of studies at that time failed to be successful.[39] Randomised controlled trials are often considered to be the most suitable method to evaluate any new intervention. However this can be difficult in clinical practice and delay the introduction of useful educational programmes and techniques. The Düsseldorf group has described a phased evaluation which may be a more suitable method to evaluate education programmes.[38] This includes programme modelling with small groups followed by exploratory trials and finally randomised controlled trials before long-term implementation, and this approach has been used with much success in Düsseldorf.

1.1.6 Group Education versus Individual Education

Diabetes education requires a different approach by health care professionals and requires a move from a traditional medical model to more patient-centred education and management.[40] The traditional model is mostly led by the professional with patient goals decided by the health care professional. This model is more suited to acute medical problems. Patient-centred care is more interactive and goals are negotiated with the patient. This model is better suited to chronic disorders such as type 1 diabetes. The delivery of education in a group format is also more suited to this patient-centred model as in itself it changes the dynamic between health care professional and patient. Group sessions can also be a more cost-effective means of delivering education[41] which is important as the costs of treating diabetes and the complications rise.

A few studies have compared the group approach and individual education in type 2 diabetes and they have shown improved levels of glycaemic control, in patients who participated in group education, as well as improvements in health-related quality of life.[42;43] There are no randomised control trials comparing group education and individual education programmes in type 1 diabetes. The DAFNE programme and the Bournemouth Type 1 Intensive Education Programme have shown that group-based education programmes can be successful but both programmes have only been compared with conventional care. However, the Guernsey Diabetes Centre has demonstrated that patients can be successfully transferred onto intensive insulin therapy, using an individual approach, and achieve sustained improvements in glycaemic control.[44]

Reviews and meta-analyses only provide information on the effectiveness of diabetes self-management education and not on the effectiveness of a group format. It can also be difficult to discern whether the outcomes are a result of a specific educational approach or a specific intervention applied to a particular population. Often studies compare group programmes with standard care rather than individual care and again this makes it difficult to assess the effectiveness of a group format. The degree of individualisation and group interactivity can also vary depending on the format of the programme. It can therefore be difficult to apply the results of some studies to different interventions and populations as it is not clear which factors result in improved outcomes. [45] Most education is now offered in a group setting as this encourages peer support and does not stretch limited resources.[12] Group programmes help patients to validate their own experiences and accurately assess the seriousness of their own condition.[46] The optimal group size is yet to be determined but groups of more than 10 people may limit the interaction between health care professionals and patients and therefore limit the effectiveness of a session.[43]

1.2. Communication

1.2.1 Clinic Consultations

The traditional model of regular appointments with a physician and individual ad-hoc nurse or dietician review is still the most common mode of review in diabetes care. This may not be the most suitable environment to facilitate self-management skills. There can be a significant discrepancy between the patient's and professional recall of the topics discussed in an individual consultation and as a result few changes in self-care behaviour are likely to occur.[47] Health care professionals often complain that consultation time is limited and it can be difficult to address psychosocial issues. However physicians who respond to patient's emotional clues (i.e. psychological and social concerns) often have shorter clinic visits.[48]

The clinic approach may therefore be inappropriate as diabetes care becomes more patient-centred and interactive. Group visits may replace the traditional model and can integrate both patient education and clinic visits whilst involving more members of the multidisciplinary team. This system has been studied in adolescents and adults with type 1 diabetes. Group visits have been shown to improve quality of life outcomes in older adolescents but had no impact on mean HbA1c levels.[49] Trento and colleagues have also conducted a randomised control trial comparing group care and individual clinic visits for 62 adults with type 1 diabetes.[50] After three years' follow-up, significant improvements in quality of life, knowledge and health behaviours were seen in patients who had group care. Mean HbA1c decreased in both groups but there were no significant differences between the two groups. These studies have shown that group care can be effective in terms of quality of life and cost but adjustments to this group format may be needed to have an effect on glycaemic control.

1.2.2 Transactional Analysis

Transactional analysis was developed by the psychiatrist Eric Berne during the late 1950s. Berne postulated that there are three ego states– Parent, Adult and Child which are shaped through childhood experiences. Some aspects of this theory can help to explain how medical consultations can be affected by the interpersonal relationships between health care professional and patient. Each ego state may influence individuals internally by affecting the way they think or externally by affecting the interaction with others. The Adult state is rational and logical, the Parent state critical but the Child state often leads to maladapted behaviour. Most consultations should be on an Adult-Adult basis. However, the patient may choose to operate from a Child role because they find this reassuring and less challenging, particularly in diabetes consultations. The instinctive response from the health care professional is to reply as a critical parent and chastise the patient. This is detrimental to the dynamic of the consultation and does not encourage patients to make their own decisions. As a result patients are unlikely to change their behaviour or develop their own self-management skills which are necessary in type 1 diabetes.[51;52]

1.2.3 Empowerment

The concept of 'empowerment' has been used to describe the encouragement of patients as equal partners in decision-making as well as the redefining of patient and health care professional roles in collaborative care.[53;54] Empowerment is not just a change in language during the consultation but a change in the power relations between patient and professional interactions, and may be a useful concept for improving communication in consultations.[55]

Anderson and Funnell have developed a six session patient empowerment programme for people with diabetes.[7] The programme was initially studied as part of a randomised wait-list control trial. The intervention group showed improvements in self-efficacy and diabetes attitudes and a significant reduction in HbA1c levels. Empowerment could therefore be an effective approach in educational interventions.

However, health care professionals who perceive themselves to be open to patient participation may actually present themselves as experts and marginalise the patients' role. Professionals may also make assumptions about patients' goals without validation from the patients themselves[55] and individuals with chronic diseases are often told off when they make their own self-care decisions.[53] This may be the result of professionals' belief in firstly themselves as the expert and secondly in physiological indicators as the only measures of a patient's health status.[56] These issues and the ways in which health care professionals hinder patients' decision making need to be studied further in order to allow the philosophy of empowerment to be used in the clinic setting or educational interventions.

1.3 Psychosocial Barriers to Self-Management

1.3.1 Depression

Early reviews and meta-analyses have suggested that the prevalence of major depressive disorders is significantly higher in people with diabetes compared with the general population.[57;58] However the studies used different methodologies to assess depression and included mixed samples of people with type 1 and type 2 diabetes. The psychological reaction to developing type 1 diabetes is likely to be different to type 2 because of the varying age range of patients, duration of diabetes, co-morbidity and management. Mixed sample studies are unlikely to be representative of either population. A recent systematic review evaluated studies which looked solely at people with type 1 diabetes and found the prevalence of clinical depression was 12.0% compared with 3.2% in the control group[59] but data from a type 1 diabetes clinic population in Bournemouth has suggested that the rates of depression are similar to that found in the general population.[60]

Depression when present in people with diabetes is associated with poorer glycaemic control[61] and as a result depressed individuals have a higher risk of diabetic complications.[62] Diabetes-related complications also contribute to higher rates of depression, particularly in those who have three or more complications.[63] The directional nature of the relationship between depression and diabetes is unclear.[64] They may exacerbate each other at a neuroendocrine level although the hopelessness of depression may contribute to a vicious circle of poor self-management, worsening glycaemic control and an exacerbation of depression.[65] Depression is also associated with increased rates of smoking and substance abuse.[66] This can further compromise self-management and glycaemic control which is generally associated with decreased quality of life and increased health expenditures. Treating depression may result in improvements in glycaemic control[67] but antidepressants are not always effective in people with diabetes.[68] This may be explained by diabetes-specific issues and a recent survey in Croatia, Holland and England showed that diabetes-specific emotional problems were common in patients with high levels of depressive symptomatology.[69] This would suggest that treatment of depression may be improved by dealing with diabetes-specific issues.

1.3.2. Anxiety

Anxiety may be a more significant problem for people with diabetes than depression.[70] The fear of hypoglycaemia, possible complications and guilt regarding poor diabetes management are the most common factors which can contribute to higher levels of anxiety.[71] Gender and socioeconomic status can also impact on anxiety and women and those with less education are more likely to report symptoms consistent with significant anxiety disorders.[72] An anxious, emotional coping style is also associated with increased stress as well as reduced regimen adherence.

As with depression it is difficult to determine the prevalence of anxiety in people with diabetes, as stress has often been used interchangeably with anxiety.[70] One study identified that anxiety disorders were present in 15% of people with diabetes although higher levels of anxiety symptoms were present in 40% of patients.[73] Anxiety levels in patients attending clinics in Bournemouth were found to be similar to those found in the general population although female patients reported significantly higher anxiety levels than males.[74] A meta-analysis has found that anxiety disorders are associated with hyperglycaemia and therefore it is possible that treatment of anxiety disorders may improve glycaemic control.[75] Anxiety only accounted for a small variance in HbA1c in this meta-analysis but this may become more significant in clinical practice as small improvements in glycaemic control can significantly reduce the risk of complications.[2] However the small number of studies and the small sample sizes limits the results of this meta-analysis.

Diabetes-specific distress may be a more useful measurement than general anxiety levels in people with type 1 diabetes. Individuals living with type 1 diabetes have to cope with blood glucose fluctuations, the prospect of complications, the continuing need for blood glucose monitoring, the frustration of poor control despite ‘compliant’ behaviour and the dilemma of disclosing the diagnosis to family, friends and work colleagues. There may be more specific stressors such as needle phobia, fear of injecting and blood glucose monitoring and the fear of hypoglycaemia. This distress can trigger a negative cascade which involves diminished motivation, less active diabetes self-care and a poorer quality of life.[70] This in turn is associated with worse long-term glycaemic control and more diabetes complications.[71] Resolving diabetes related distress may be beneficial in improving glycaemic control.[71] The Problem Areas in Diabetes (PAID) questionnaire has been developed to assess the patient’s perspective on the burden of diabetes and its management and is a valid measurement of diabetes-related distress.[71]

1.3.2.1 Psychosocial issues and Structured Education

Psychological problems such as diabetes distress and depression are likely to have a significant impact on patients’ responses to structured education. However it is also possible that structured education can be used to reduce levels of psychological distress. Currently the evidence to support these theories is limited. The Düsseldorf group has developed an effective structured education programme but they have identified patients who continue to have low levels of diabetes knowledge and poorer glycaemic control despite attending the programme.[22;26] Psychosocial factors may contribute towards these problems. More holistic programmes have been developed but their impact appears to be limited to improving hypoglycaemia only and not glycaemic control.[27] This is an important area and more studies are needed to clarify the relationship between psychosocial difficulties and diabetes education.

1.3.3 Eating Disorders

The prevalence of eating disorders in individuals with type 1 diabetes is still under debate. Eating disorders have been shown to be more prevalent in adolescent female with type 1 diabetes (10%) compared with non-diabetic subjects (4%)[76] but other studies suggest that the prevalence of eating disorders is equivalent to non-diabetic peers.[77-80] Eating disorders in adolescents with type 1 diabetes are associated with insulin omission for weight loss and impaired glycaemic control.[81] It is difficult to distinguish between eating disorders and normal dietary concerns and such disorders are often under-diagnosed and untreated.[70]

1.3.4. Psychosocial Interventions

There is a need for effective psychosocial interventions which help people to deal with the daily demands of diabetes.[82] Treatment regimes are becoming more intensive and require the patient to make significant behavioural changes.[83] Psychosocial support may be necessary to help people maintain behavioural changes which sustain improvements in glycaemic control and quality of life.[84] Psychological interventions have been shown to improve glycaemic control in children and adolescents but the data for adults with diabetes is scarce. The majority of studies use cognitive behavioural therapy and the methodology is variable.[85] Cognitive analytical therapy may be more useful but there is only one study which examines its use in patients with poorly controlled type 1 diabetes.[86] The results of this study showed sustained improvements in glycaemic control as well as improvements in interpersonal difficulties but the sample size was small. Group counselling programmes have the added advantages of emotional support from people with similar experiences and enhance a sense of belonging and emotional well-being.[87] Behavioural group programmes have been used to teach coping strategies to help overcome the fear of complications and reduce avoidance behaviour. Improvements in disease acceptance and psychological well-being have been seen but the effects on glycaemic control are variable.[88;89]

1.4. Health Behaviour Models

Behaviour change is required for people with diabetes to develop and maintain good self-management skills. There are a multitude of factors which can influence human behaviour particularly in relation to health education. A number of models have been developed to help explain human behaviour. A single model cannot be used to provide all the answers for behaviour change but they can be used to help develop educational interventions so that outcomes can be improved.[90] The models would suggest that it is important to be aware of the patients' 'perception of diabetes as a personal threat', the perceived costs and benefits of change and individual, peer and family beliefs[91] as this will result in more effective communication and allow the professional to tailor the treatment to the needs of the individual.[82]

1.4.1 Health Belief Model

The Health Belief Model (HBM) was first adapted by psychologists in the 1950's to explain why people would not use available preventative services such as influenza immunization. Becker developed the model further in the 1970's and it was used to predict preventative health behaviours as well as the behavioural response of patients to treatment.[92] This model suggests that health actions are a result of certain core beliefs. These beliefs are:

- Perceived susceptibility or the chances of developing an illness.
- Perceived severity of an illness.
- Perceived benefits i.e. the person's opinion of how effective an advised action may be in reducing the risk or seriousness of an illness
- Perceived barriers or the person's opinion of the physical and psychological costs of the advised action
- Cues to action. These are events which may motivate the patient to change their behaviour. They may be internal e.g. breathlessness or external e.g. health education leaflets.

These core beliefs can be used to explain health related behaviours but may also help to identify change strategies and develop messages that can persuade individuals to change their behaviour. The health behaviour model does have some weaknesses.[93] Firstly, some studies have reported conflicting findings and healthy behaviours have been associated with low perceived severity[94] and low susceptibility.[95] Secondly, the model does not examine the role of social, economic or environmental factors and does not take into account emotional factors such as fear and denial.[93]

1.4.2. Stage of Change

Prochaska and Di Clemente developed a ‘Stage of change’ model which describes the process through which individuals progress when changing behaviour.[96] The stages are pre-contemplation (individuals are not considering changing their behaviour), contemplation (thinking about change in the next six months), determination (individuals have decided to change their behaviour), action (individuals are actively changing their behaviour) and maintenance (the individuals have changed their behaviour and sustained these changes). People become more committed to change as they progress through the different stages although it is possible to relapse back to earlier stages.[97] In order to encourage behaviour change the practitioner can tailor the intervention to the patient’s stage of change.

1.4.3 Theory of Planned Behaviour

The theory of planned behaviour, developed by Ajzen and Fishbein, suggested that a patient’s expressed intention is the best predictor of their subsequent behaviour. There are two aspects which determine the patient’s behavioural intentions. The first determinant is the influence of the social environment and whether people whom the patient perceives as important value the behaviour change. The second determinant is the attitude of the patient and how important the patient values the behaviour.[98]

1.4.4. Self-efficacy

The concept of self-efficacy is an important part of behaviour change. Self-efficacy is defined as a person’s confidence in their ability to produce a certain level of performance in order to achieve a desired goal.[99] Individuals with high levels of self-efficacy are more likely to set themselves challenging goals, maintain commitment to them and persevere in adverse situations. Higher levels of self-efficacy in people with diabetes have been shown to be associated with better adherence to dietary self-care,[100] blood glucose monitoring[101] and glycaemic control.[102] Self-efficacy, with diabetes-related support, has also been shown to be associated with better psychosocial functioning. Self-efficacy is dynamic and changeable and levels may improve after behavioural interventions.[103] In adolescents with type 1 diabetes, coping skills training with intensive diabetes management has been shown to improve glycaemic control and diabetes self-efficacy.[104;105] The Confidence in Diabetes Scale is a reliable measurement of diabetes self-efficacy but further research is needed to establish its predictive value and responsiveness.[87]

1.5 Summary

Type 1 diabetes is a chronic, lifelong disorder which requires high levels of self-management skills to attain good glycaemic control, without hypoglycaemia, and with as little disruption to lifestyle. A number of different factors contribute to the success of patient's self-management skills. Patients need to acquire knowledge through education programmes but also need the desire to apply these skills on a daily basis. Living with diabetes can have a significant psychosocial impact on the individual. Psychosocial factors such as depression and anxiety or diabetes-related distress can act as barriers to self-management. A significant number of patients do not manage to achieve good self-management skills and struggle to maintain good glycaemic control despite the availability of patient-centred education programmes. The traditional hospital approach in the UK and lack of recognition and treatment of psychosocial barriers may also be obstacles to developing the necessary self-management skills. This highlights the need for further research to identify from the patients' perspective why some of our patients do not develop good self-management skills and good glycaemic control. The current hospital service, for people with type 1 diabetes can then developed to better suit patients' needs.

1.6 Aims

The aims of the thesis are as follows:

- to evaluate the traditional hospital service and in particular clinic visits using focus groups

- to develop and evaluate the structured education programme for patients with newly-diagnosed type 1 diabetes using semi-structured interviews and psychological screening questionnaires
- to evaluate biomedical and psychological outcomes of the Bournemouth Type 1 Intensive Education programme
- to determine why some patients do not improve their glycaemic control following the Bournemouth Type 1 Intensive Education Programme using semi-structured interviews and qualitative analysis
- To evaluate the use of motivational interviewing in patients who did not improve their glycaemic control following the education programme.

2 Methods

2.1 Qualitative Research

Qualitative research is defined by researchers studying subjects in their natural setting and capturing individuals own perspective and meaning.[106;107] The aim of qualitative research is to answer ‘how’ or ‘why’ certain experiences are created[108] and how it feels to experience particular conditions such as living with a chronic illness.[109] Qualitative researchers study a process rather than outcomes and participants should be studied in their natural surroundings i.e. where they live or work to allow the process to continually change and develop.[109]

The origins of this research are in sociology and social anthropology but more recently these methods have been used in health research to improve understanding of health behaviour and health services.[108] Public health issues are increasingly related to human behaviour and therefore social research using qualitative methods may help us to reach a better understanding of those issues and improve health care services. Qualitative research is important as it may answer questions that quantitative research cannot.[110]

Green and Thorogood suggest that qualitative methodology covers a range of different approaches. These are the interpretative, social constructionist and critical approaches. The interpretative approach focuses on individuals interpretations of their world rather than the reality of their world. The aim of this approach is to understand human behaviour which can be complex and unpredictable. Health research projects which use qualitative methodology often use the interpretive approach as it concentrates on the meaning of phenomena such as symptoms and health behaviours.[108] Social constructionism focuses on how phenomena are created, the process by which diseases are classified and the implications of this classification. The process of classification is often based on historical, social and political processes rather than a better understanding of the disease itself. This interpretive approach aims to understand ‘reality’ whereas the constructionist approach challenges pre-existing realities. The critical approach combines epistemology or the theory of knowledge with critique. The aim of this approach is to dismantle the status of knowledge and the process through which it has gained acceptance.

The different approaches described above will generate different research questions. However there are a number of perspectives which are shared by all researchers using the different approaches. These are naturalism, a focus on understanding and a flexible research strategy. The study of phenomena and health behaviour in their 'natural' environment is called naturalism. Individuals may alter their behaviour when participating in a study. Therefore interviewing participants in their natural environment and letting them tell their own story can often result in a better understanding of their views and behaviour. Ideally the researcher should aim to reduce their impact on the study by becoming part of the setting before the study begins. However this is not always possible and the researcher needs to reflect on the impact on their behaviour on the study participants.

The focus of qualitative research is to understand the participants' perception of the world. The researcher should have no preconceptions about the participants' behaviour or views. They should also assume that most individuals make rational choices most of the time and aim to understand that the choices made are dependent on the constraints that the individuals are under as well as their varying priorities. Researchers should not assume that the participants are acting incorrectly or irrationally but focus on the things they achieve with their behaviour and how they achieve it. All participant perspectives are valid. This type of research is beneficial in healthcare as it can give healthcare professionals a more empathic understanding of patients' behaviours and therefore add support to ideas for behaviour change or health promotion.

All research studies need careful planning but qualitative research strategies allow a more flexible approach. The researcher can make adaptations throughout the study depending on whether the sample size needs to be increased or whether different methods need to be incorporated into the study. This flexibility is more useful in health research as a shift in perspective of the researcher may be needed as the study progresses and different issues which were not anticipated arise.

2.1.1 Qualitative Research versus Quantitative research

Quantitative research has often been seen as the most influential research in health care and it is thought to be reliable as research findings can be scrutinized using statistical methods.[111] However quantitative research uses a rigid approach which often makes it difficult to explore complex human emotions and their patients' attitudes. Qualitative research uses a different approach. Research results can be used to provide important information about patients' views and satisfaction and this can be used to develop and improve patient care. Qualitative research is often perceived by critics to use a non-scientific approach and small sample sizes are also cited as a weakness. Another criticism is interviewer bias, although this can become a strength of the research provided the researchers are clear about their beliefs and experiences. However rigorous research methods are also required for good qualitative research. More recently some studies have adopted a different approach using both qualitative and quantitative research and this has the added advantage of ascertaining problems from different view points.[106]

2.1.2 Rigour in analysis

The credibility of qualitative research is often questioned and therefore it is essential to have guidelines that ensure reliability and validity. The process of analysis should be systematic, with agreed rules and processes against which the results can be evaluated.[112] The principles which add credibility are transparency, validity and reflexivity. Transparency is the clarity with which the analytical methods used in qualitative research are outlined. A truthful and clear description of the approach used should always be provided. Validity can be defined as the extent to which the research answers the question that it aims to answer. Qualitative research has several advantages which help to ensure validity. The methodology is flexible and offers participants the opportunity to challenge the researcher's assumptions particularly through feedback. Individuals are also studied in real-life settings and no extrapolation from artificial settings is needed. Testing the emerging theories is an essential part of improving validity. Researchers should look for cases which deviate from the emerging theories and they should be accounted for rather than discounted.[108] Researchers are also required to practise reflexivity i.e. review their role in the study to make sure that they do not impose their own meaning on the data. Representativeness is important and researchers should be able to extrapolate their findings to the general population. Ideally participants should be representative of the population studied but this can be difficult if the research involves small numbers of participants.[109]

2.1.3 Methods

2.1.3.1 Focus Groups

Focus groups have been used more commonly for market research and political decision making but they are now used for evaluating health interventions. They can be used to gain large amounts of information in a short time as well as create ideas for future research.[113] Focus group participants exchange ideas and this can also stimulate deeper thinking about a subject.[106] The role of researcher is one of a moderator. One of the advantages of this methodology is the variety of data that is expressed by the groups.[106] The group interaction is more likely to create data which reflects everyday life and can also prevent individual participants from expressing false information.[114] Focus groups not only allow participants to qualify their responses but researchers can also explore the responses in more detail.[115] The focus group members are able to respond and comment on other participants' statements which can then either be developed further or challenged.[109]

The difficulties in using this method relate mainly to the dynamics of the group. A dominant individual may exclude quieter members and polarize the group.[115] As a result some individuals may feel too intimidated to speak or express their true opinion**.** It is essential that the interviewer is aware of these issues in order to manage the group effectively and encourage more reserved individuals.[108] Recruiting appropriate participants is an important part of focus group methodology. Ideally participants should have similar backgrounds and experiences to aid good, open discussions.[113] It is essential to make the groups feel comfortable as participants are then more likely to disclose personal experiences relevant to the research question.

2.1.3.2 Semi-structured interviews

Semi-structured interviews can be a useful way of collecting data which can be analysed in a number of different ways. Individuals are more likely to express their views in a semi-structured interview than in a standardized interview or questionnaire.[116] The interviewer sets the agenda in semi-structured interviews but it is the interviewee who influences the type of information which is produced on each topic.[108] The basis of these interviews is ‘subjective theory’. Subjective theory suggests that participants firstly have a comprehensive knowledge of the research topic and secondly they have beliefs that they can readily express when answering open questions. However the participant will also have implicit beliefs that can be difficult to express without certain methodological aids or questions. There will be several topic areas which need to be answered in the interviews. Each topic should begin with open questions which can be answered with the knowledge that the interviewee has at hand. Theory driven questions which are based on the interviewer’s presuppositions follow the open questions and aim to explore the interviewee’s implicit knowledge. Finally each topic should end with confrontational questions which aim to re-examine the beliefs that the interviewee has expressed and present viable alternatives.

2.1.4 Analysis

Over the years there has been little emphasis on analytical methods in qualitative research. However with the increase in health studies using qualitative methods it became more necessary to define the different ways in which data could be analysed. Qualitative analysis requires the researcher to have a broad perspective on the history, social structures and characteristics of the research participants as well as a broad knowledge base. Describing a set of rules that integrated all these different aspects was difficult but several researchers developed analytical methods which can be reproduced in different studies. In reality most researchers use a mixture of approaches but the most common approaches are grounded theory and thematic analysis.[108]

2.1.4.1 Grounded Theory

Grounded theory was developed by two American sociologists, Barney Glaser and Anselm Strauss.[117] They developed a method which allowed the generation of new theories from the data i.e. the theories are 'grounded' in the data. The process of grounded theory initially involves identifying different categories or concepts within the data. Each line is analysed and given a code. The labelling of the categories should be analytical and not descriptive. Emerging theories should be continually challenged and developed until there is theoretical saturation i.e. no new categories can be identified. Links and relationships between the categories can then be established.[109]

There are some limitations to grounded theory. The fundamental aim of grounded theory is the development of new theories. These theories may or may not have implications on policies and practice in health services and may not be the best analysis to use in healthcare studies. There is also little reflexivity in grounded theory and the data is often fractured to develop theories rather than preserving individual accounts.[108]

2.1.4.2 Thematic Analysis

Thematic or framework analysis is not dissimilar to grounded theory. However this form of analysis aims to protect the integrity of respondents' narratives. The researcher should become familiar with the narratives through listening to tapes and re-reading transcripts. The next step for the researcher is to develop 'codes'. Codes are a list of themes that are usually causally related. Each theme is a pattern found in the data that aims to describe and interpret different aspects of the data. In thematic analysis the theme may be developed directly from the narratives or generated from previous research and theories. Finally the relationships between the codes are examined and can be used to develop practical strategies to improve healthcare.[109;118]

2.2 Psychosocial Questionnaires

2.2.1 Introduction

Quality of life has become an important outcome in health research and particularly in diabetes research. Assessing quality of life may help healthcare professionals to understand better the outcomes which are important to patients.[119] Diabetes is consistently associated with impaired health-related quality of life (HRQOL) levels and this may impact negatively on diabetes self-management skills.[120] HRQOL encompasses three fundamental domains which are biological functioning, psychological functioning and social functioning. Assessment of these three domains should be routine in the management of diabetes patients particularly as it has been shown that monitoring and discussion of psychological well-being in the outpatient setting can have positive effects on mood and satisfaction in adult patients.[121] The assessment tools used are in the form of questionnaires. Previously questionnaires which had been developed in the general and psychiatric population were used to evaluate psychiatric well-being.[122] However these questionnaires were limited as symptoms which were considered to represent depression or anxiety could also represent symptoms related to diabetes or diabetes complications.

There is little agreement on the best way to assess HRQOL in diabetes .[123] Polonsky maintained that researchers looking at QOL should follow certain rules when choosing questionnaires.[124] These are choosing questionnaires because they have featured in other studies, using questionnaires for QOL and psychological well-being interchangeably and using questionnaires with quality of life in the title. This may misrepresent the results from research studies and potentially affect the benefits of therapeutic interventions. A number of questionnaires have now been developed specifically for assessing psychological well-being in people with diabetes and two of these, the Diabetes Health Profile[122] and the Problem Areas in Diabetes[71], were chosen for use in this project. The other questionnaires used were the Hospital Anxiety and Depression Scale[125] and the Rosenberg Self-esteem scale.[126]

2.2.1.1 Diabetes Health Profile (DHP)[122]

The DHP is a self completion questionnaire which was specifically developed for people with type 1 diabetes following in-depth interviews with both patients and health care professionals. The questionnaire has 32 items but the authors developed three subscales using factor analysis. These are Psychological Distress, Barriers to Activity and Disinhibited Eating. The reliability of these subscales is good with Cronbach's alpha scores of 0.86, 0.82 and 0.77 respectively. These subscales also measured psychosocial issues which had not been found in other questionnaires used at the time.[127]

2.2.1.2 Hospital Anxiety and Depression Scale (HADS)[125]

The HADS questionnaire (appendix 1) was developed in 1983 by Zigmond and Snaith. The aim of the questionnaire was to identify caseness of anxiety and depression in hospitalised individuals with non-psychiatric illnesses. There are seven subscales for both anxiety and depression which are mixed together.[128] The questionnaires have been designed to prevent interference from somatic disorders and therefore exclude questions which refer to physical problems such as fatigue or insomnia. Questions which involve symptoms that relate to psychiatric disorders were also excluded. One of the main aims for the authors was also to distinguish carefully between anxiety and depression in patients.[128]

The HADS questionnaire has been use in a large number of studies which has allowed evaluation of the psychometric properties of the questionnaire.[128] Internal consistency is an evaluation of the correlations between different items on a test or questionnaire and it is measured with Cronbach's coefficient alpha. The recommendation is that the coefficient should be 0.6 or more[129] and this has been met in all studies of the HADS questionnaire.

2.2.1.3 PAID questionnaire Problem Areas in Diabetes (PAID)[71]

The PAID questionnaire (appendix 2) developed in 1995 by Polonsky et al, was designed to measure emotional problems that relate to diabetes. However later work has suggested that it can also be a good measure of sub-clinical and clinical depression.[130] The questionnaire includes twenty items that describe challenging situations for people with diabetes and each item is rated on a 5-point Likert score ranging from 0 (no problem) to 5 (serious problem)[124]. The scores are transferred to a scale from 0-100. The questionnaire has been tested widely in Europe and scores of 40 or more are considered to represent severe diabetes-specific emotional problems[69;131]. Psychometric testing has shown that the questionnaire has high internal reliability and also sound two month test-retest reliability in a stable sample of patients. The questionnaire has been found to be significantly associated with emotional distress, disordered eating, fear of hypoglycaemia, regimen adherence, diabetes complications and glycaemic control. Multiple regression analyses that have controlled for age, duration of diabetes and general emotional distress have shown that PAID scores contribute uniquely to regime adherence and glycaemic control. This suggests that the PAID questionnaire identifies diabetes-related emotional distress. The PAID questionnaire has also been shown to be a statistically significant predictor of glycaemic control in patients who were monitored over a one year period. [71]

2.2.1.4 Rosenberg Self-esteem Scale.

The Rosenberg Self-Esteem Scale is a measure of self-esteem. The RSE consists of ten self-worth statements which are related to feelings of self-worth. Each statement is answered on a four point scale ranging from ‘strongly agree’ to ‘strongly disagree’. The RSE was originally developed to assess self-esteem among adolescents but multiple studies have used the questionnaire in both clinical and the general population showing good validity and reliability.[126]

3 Making clinic visits more effective through focus groups.

3.1 Introduction

Adjustment to the diagnosis of a chronic disease, such as diabetes, is made more difficult for individuals due to the deterioration in their physical health.[132] Living with a chronic disease such as diabetes can be difficult with constantly evolving treatment regimes and unpredictable outcomes and prognosis.[133] People with diabetes encounter numerous barriers to good diabetes control on a daily basis. However they are still required to practise effective self-management to maintain good glycaemic to delay the onset and progression of diabetic complications.[2] The way in which people are given their diagnosis and given information about the condition can vary considerably. The approach is however important as it can influence the patients' attitude towards their condition and their subsequent self-management.

Traditionally people who are diagnosed with type 1 diabetes are seen either in an outpatient setting or on the wards by diabetes specialist nurses and dieticians for diabetes education and they are given ongoing support via the telephone, hospital appointments and email. The patient was seen in the diabetes clinic shortly after diagnosis and this was typically followed by clinic visits every six to twelve months. At the time of this study patients were given the opportunity to attend the intensive education programme when necessary depending on glycaemic control and patient wishes.

Diabetes services which foster collaborative relationships between diabetes health care professionals and patients should be developed to enhance the self-management skills of patients. The aim of this study was to explore the views and experiences of people with type 1 diabetes in order to plan service changes that better meet their needs.

3.2 Methods

Focus groups of patients with type 1 diabetes in the Bournemouth area were arranged at the Bournemouth Diabetes and Endocrine Centre. All patients were invited to a focus group if they had attended the intensive education programme within the last year. Participants were asked to give consent and complete a questionnaire (appendix 3) about their clinic visits to the hospital. A discussion then followed on the first year after diagnosis and clinic visits. The discussion was transcribed and analysed for recurrent themes using qualitative analysis.

3.3 Results

3.3.1 Questionnaires

Three focus groups were held at Bournemouth diabetes and endocrine centre. A total of 10 individuals with type 1 diabetes attended the focus groups. The mean age was 44.8 ± 16.2 years with diabetes duration of 20.1 ± 15.3 years. The three groups were comprised of 6 women and 4 men.

The results of the questionnaire can be seen in table 1.

Table 1 Focus Group Questionnaires

Question given to patient	Patient Response	No. of patients (%)
1. Which healthcare professional did you see at your last clinic visit?	Doctor	100
	Other	0
2. Which other healthcare professional would you like to have seen?	Diabetes Specialist Nurse	40
	Dietician	20
	Psychologist	20
	None	20
3. Was there a specific reason for your appointment?	Yes	60
	No	40
4. What was the reason given for attending clinic?	Routine appointment	50
	Other	50
5. Did you have other issues to discuss in clinic?	Yes	30
	No	70
6. Did you have sufficient time to discuss these issues?	Yes	66
7. What issues was the health care professional interested in?	Medical results	50
	Diabetes management	60
	You as a person	30
	How are you coping	40
	All 4 issues addressed	50
8. What issue was most important to health care professional	Diabetes management	60
	Medical results	30
	Other	10

3.3.2 Group Discussion

Expectations for clinic visits were varied. One individual expected the doctor to have read the medical notes so that they had a good overview of the situation and medical problems. Another felt that they should have the 'chance to discuss how their diabetes was going, if there were any worries and personal feelings on the 'situation'. Two participants expected a general 'MOT' and results from their blood tests. Reassurance and the opportunity to have questions answered were also expected from the visit. General comments on improving the service included shorter waiting times, 'less of a rushed feeling' during clinic visits, more questions directed to how individuals are coping on a daily basis and better provisions for treatment of hypos and friendly staff. However there were also a number of themes which emerged during the transcript analysis.

Shock at diagnosis

Only one individual suspected that he had diabetes. However this was rare and receiving the diagnosis came as a shock to all the other members of the groups. It was also felt that generally, healthcare professionals had little understanding of the psychological distress associated with receiving the diagnosis and this had often been the most difficult time for participants. Depression was a significant problem and most patients felt that this had not been addressed after diagnosis or later on during their lives.

'I was quite young at the time. My parents were shocked because it was difficult. There was no recognition of this is a shock to me mentally.' (R2, female)

'I thought I had the bleakest outlook on the planet. I thought my world had ended the day I was diagnosed......it is a terrible shock.' (R5, male)

Support and Education at diagnosis

The support and information given at diagnosis was variable and often depended on the age at which they were diagnosed. However, all individuals felt there was a lack of support and easily accessible education and this hindered the ease with which they adjusted to the diagnosis. The educational content and delivery of the information was inconsistent and the approach didactic and negative.

'My initial frustration was when I first got diagnosed. I found out one day - I was in hospital and shipped out the next day with a pen and just told to inject myself. I had to see my GP to get on a training course.' (R1, male)

'The staff nurse came in and ripped into us about how dangerous this was and made everyone feel very down. This was counterproductive….I remember this stunned silence.' (R5, male)

Meeting other people with diabetes

Only one participant knew another person with type 1 diabetes. Often, the intensive education programme was the first opportunity that the participants had to meet and talk to other people with type 1 diabetes. This was a common theme throughout both focus groups and felt to be particularly important to all the participants. There were many benefits to meeting other people with type 1 diabetes. Sharing experiences relating to self-management difficulties was perceived to be essential in helping participants feel less isolated, particularly if they met others who had encountered similar problems. One individual felt that being able to pass on the benefit of his experiences was a positive experience not just for the recipient, but for himself as well.

'I have only just now in the job that I am in, met two other people with diabetes. We can talk about it or talk about differences in each others lifestyles; stuff like that is really helpful.' (R1, male)

'The first time I hardly knew anyone. At work there were two people with type 2 diabetes. When I came here to do this education thing that was the first time I had actually spoken and heard about other diabetic's goings on – and you can say yes – that happens to you.' (R6, female)

‘Coming here and actually being able to talk to people was much more useful than you would have imagined.’ (R7, female)

Psychological Support

There were other issues that affected the patients psychologically other than at diagnosis. They felt that there could be difficulty adjusting to erratic blood sugars and they did not react well to what they perceived to be less than perfect control. On the other hand, motivation to deal with intensive insulin regimes can also be hard to find. The individuals who had seen a psychologist found this support particularly helpful and felt it should be offered to all people with type 1 diabetes. However, there was recognition that not everyone would be receptive to psychological therapy.

Clinic Visit Problems

The groups felt that time appeared to be limited at clinic visits. They did however have an appreciation of the pressures on staff and time at these clinics. There was a perception that doctors had not always read the notes and did not know about meetings with other health care professionals. At times, clinic visits could be intimidating and rushed and the doctor was often only interested in medical results. Consequently, patients often forgot about issues which they needed to talk about. It was felt that social and personal questions should be part of the routine consultation in order to cover all relevant issues.

Continuing education

Diabetes treatments are continually evolving and all members of the group were keen to keep up-to-date with new therapies. The need to learn more about diabetes complications and a better understanding of the progression of complications was also expressed.

‘My mum or gran will always ring up about new treatments that they have read about. I don’t know anything about it. It would be nice to look at it and say ‘oh, it is at a trial stage’. (R1, male)

'I had a bit of trouble with my eye recently. I would like to know the system by which it progresses – what checks you have and what the laser complications are and then I can adjust to it. Knowledge is power.' (R5, male)

3.4 Discussion

The aim of the focus groups was to determine the patients' perception of clinic visits and the diabetes service. Three focus groups were held and information was provided about clinic visits. The questionnaire results suggest that 80% of patients would have preferred to see another healthcare professional at their clinic visit, 34% felt that there was not sufficient time to discuss their problems their concerns and 50% of patients believed that their concerns were not fully addressed. This suggests that the current clinic format may not be the most suitable approach for patients with type 1 diabetes. This may in part be related to the consultation with the physician. Kaplan et al studied individual patient consultations.[134] They found that consultations in which the physician is less dominant, listens more, facilitates patient questions and expresses more negative and positive emotion result in better patient knowledge and improved self-management. Current resources often limit the time available for consultations but training healthcare professionals to adopt a counselling approach using open questions may be more helpful. Group sessions were also felt to be important to people with diabetes as they provide a better support network and reduce feelings of isolation which can otherwise arise. Addressing psychosocial difficulties and receiving support from other health care professionals such as psychologists was seen as essential. A group format would allow patients to see different members of the team including a psychologist, meet other individuals with diabetes and increase the time for consultation. Trento et al[50] have shown that a group format can be successful for patients with type 1 diabetes but some patients would also need an individual consultation. Some patients in the focus groups found the clinic structure quite rigid and felt there was a need for more flexibility and intensive input at difficult times. They suggested that a drop-in clinic may be helpful. Drop-in group clinic appointments have not been evaluated in diabetes care but they have been shown to reduce waiting times and increase patient satisfaction in other chronic diseases.[135]

The area of most importance appeared to be the time of diagnosis. Receiving the diagnosis of diabetes can be a very difficult time and the focus groups reported a significant degree of psychological distress. The groups suggested that more support is required at diagnosis and better flexibility required when visiting health care professionals at that time. Continuous education was also seen as an essential part of diabetes care and necessary to help improve self-management skills. However knowledge alone does not result in enough changes in self-care behaviours to achieve optimal glycaemic control.

The information from the focus groups suggests that services at the time of diagnosis needed to be improved. This information is not dissimilar to the findings of the Listening Project which was commissioned by Diabetes UK in 2002.[136] The report, based on focus groups and on-to-one interviews identified that people diagnosed with diabetes require more time to discuss the diagnosis with health care professionals and peer support opportunities which can reassure and identify common challenges with diabetes management. The future challenge for diabetes teams is to design a care pathway for people with type 1 diabetes which meets the needs of patients at the time of diagnosis and throughout their life. The approach needs to be integrated and patients need more flexibility and continuity from health care professionals. Education and support provided in a flexible and interactive manner is likely to empower the patient and improve self-management.

4 Living with Diabetes Programme

4.1 Introduction

The focus groups showed that people with type 1 diabetes experienced high levels of psychological distress at the time of diagnosis and highlighted the need for better support and education at that difficult time. The high levels of psychological morbidity in patients at diagnosis can impact on the acquisition of self-management skills and glycaemic control[64;75] The levels of psychological distress at diagnosis may be much higher than at any other time and similar to the reaction to a bereavement or terminal illness.[137] When some patients are informed about the diagnosis, they may go through a series of reactions such as disbelief, anger, bargaining and depression before acceptance. Psychological distress and denial in adults with diabetes at diagnosis may be a stronger predictor of late complications than psychological difficulties that occur later in the disease process. This would suggest that improving levels of psychological distress and disease acceptance at diagnosis may have an impact on glycaemic control and diabetes complications.

Prior to this study, support for patients with newly-diagnosed type 1 diabetes was provided by the multidisciplinary team. However, this support was unstructured and the input variable for each patient with more intensive input during the first few weeks after diagnosis. The information from the focus groups as well as previous experience of structured education prompted the development of the Living with Diabetes (LWD) programme to provide appropriate support and education at diagnosis from health care professionals combined with peer support. NICE encourage the use of structured education programmes for people with diabetes but there is little guidance on the content of the programmes.[138] Few programmes for people with type 1 diabetes are available at diagnosis. Spiess et al carried out a randomised control trial to look at the effects of an onset distress reduction programme for patients with newly-diagnosed diabetes.[139] Their results showed a reduction in levels of depression and less anxious coping behaviour but there was no difference in glycaemic control between the two groups. However a reduction in denial at diagnosis may lead to improvements in self-management skills and better glycaemic control in the long term. There are specific components of patient education which appear to predict improvements in glycaemic control. These are face-face interaction, physical exercise and the use of cognitive re-framing teaching methods.[140] The duration of an intervention does not seem to be important although the timing of a programme after diagnosis may be significant.

The goal of the LWD programme was to provide better structured support for people with newly diagnosed diabetes including peer support in the first year after diagnosis thus reducing levels of psychological distress and improving disease acceptance. The aim of the study was to evaluate the impact of the programme on psychosocial distress and to determine patients' attitudes towards their diabetes after their first year of diagnosis using qualitative methods. This was achieved by conducting semi-structured interviews with patients who attended the LWD programme and a group of patients who received 'conventional care' at a neighbouring diabetes centre (Poole General Hospital). .

4.2 Methods

4.2.1 Living with Diabetes programme

The Living with Diabetes programme was devised as a group education programme and was 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 other people. This process requires individuals to pay attention to the model or the situation, retain the information and reproduce the behaviour. However observational learning can only be successful if the individuals' behaviour has rewarding consequences and if the original model is admired and similar to the observer.[99] Cognitive reframing is a teaching method which provides alternative perceptions to the person with diabetes which may be more advantageous to their self-management skills. All patients diagnosed with type1 diabetes in general practice were referred immediately to the Bournemouth Diabetes and Endocrine Centre. They were initially reviewed by a diabetes nurse specialist and commenced on insulin treatment. Individual appointments with diabetes specialist nurses and dietitians were arranged over the first 4-6 weeks,

followed by a consultant clinic visit. Patients were then encouraged to attend the Living with Diabetes programme over the following year. Patients who did not attend received ongoing education as necessary with both diabetes specialist nurses and dietitians.
The programme consisted of four sessions at three-monthly intervals with each session lasting for 2 hours. Each session was led by either a diabetes specialist nurse, diabetes psychologist, diabetes dietitian or diabetes doctor using a non-didactic approach. Each session began with a general discussion. Patients were then encouraged to discuss any anxieties about their diagnosis or management and any other issues pertinent to their diabetes within small groups. This was followed by small group discussions which focused on questions prepared by the facilitator. Each facilitator would concentrate on topics related to their speciality. However the main topics of discussion were based on blood glucose monitoring, carbohydrate counting, hypo and hyperglycaemia, dietary issues, diabetes complications and any fears and anxieties regarding diagnosis. Subsequently each patient had a weight and blood pressure check followed by an opportunity for individual consultation with a diabetes doctor. Each patient also had the opportunity to speak with any of the healthcare professionals or arrange an individual appointment at a later date.

4.2.2 Outcome Measures

Biomedical data was collected from the participants at baseline and 12 months. Participants were asked to complete psychological screening questionnaires at all four visits. The questionnaires used were the Problem Areas in Diabetes (PAID) and the Hospital Anxiety and Depression Scale (HADS). The baseline questionnaires were completed in the first three months following diagnosis and the data compared to follow-up data using paired t-tests. The baseline and one year biomedical data were compared to biomedical data for patients who had chosen not to attend the Living with Diabetes programme and who had conventional management at Royal Bournemouth Hospital (RBH) and with those who received conventional care at Poole General Hospital (PGH). Conventional care in this study was considered to be the approach that had been in use in most diabetes centres over the last dew decades. This approach was largely ad-hoc and not based on any guidelines. All patients referred to Royal Bournemouth Hospital (RBH) and Poole General Hospital (PGH) would have an initial visit with a diabetes specialist to start insulin therapy and a clinic visit with a diabetes physician within two months of diagnosis. However the care following these visits would be limited to telephone calls and six-monthly clinic visits. The diabetes centres at RBH and PGH work closely together, developing joint guidelines and holding joint meetings with the primary care sector. It is also common for diabetes specialist nurses and junior doctors to have worked in both units. For these reasons, conventional care was considered to be similar in both centres

4.2.3 Qualitative Interviews

All patients who were diagnosed with type 1 diabetes between January 2004 and June 2005 are registered on the databases at both RBH and PGHl. All patients who attended the Living with Diabetes programme at RBH and those who had conventional treatment at PGH following diagnosis were invited to participate in this part of the study. The semi-structured interviews were conducted at the RBH or at the patients' homes. The interviews lasted for 30 minutes and interview questions were used as a guideline (appendix 4). The participants gave written consent to be interviewed and tape-recorded. The transcripts were analysed using thematic analysis with a data-driven approach. Team members reviewed the findings and reached agreement on the themes. The analysed transcripts were sent to the participants for validation.

4.3 Results

41 patients were diagnosed with type diabetes at RBHl. 31 patients attended the Living with Diabetes Programme and 10 chose not to attend: they received 'conventional' care as required.

4.3.1 Royal Bournemouth Hospital

4.3.1.1 Biomedical results for LWD group and Conventional care group

Tables 2 and 3 show the baseline and 1 year characteristics for the Living with Diabetes Group (LWD) and Conventional Group at Royal Bournemouth Hospital respectively. Table 3 shows the change in HbA1c for both groups over one year. There were significant improvements in HbA1c at 3 months, 6 months and 1 year ($p<0.001$) in the LWD group as well as a significant increase in weight and BMI ($p<0.001$). However there were no significant differences over the year for patients who had conventional treatment at either RBH or PGH. There were no significant differences in baseline HbA1c, BP, weight and BMI between the two groups. At one year the diastolic blood pressure was significantly higher in the LWD group than the conventional group ($p=0.021$) but there were no significant differences in the other variables. The change in HbA1c at one year was not significantly different between the two groups ($p=0.276$).

Table 2 Baseline characteristics of Living with Diabetes (LWD) group and Conventional (CON) treatment groups

	LWD RBH n=31	CON RBH n=10	CON PGH n=28
Age (mean ± SD)	39.4 ± 15.3	39.5 ± 16.6	
HbA1c (mean ± SD)	11.6 ± 2.1	11.4 ± 3.4	11.6 ± 2.2
Systolic BP (mean ± SD)	141 ± 22	124 ± 4	
Diastolic BP (mean ± SD)	85 ± 17	69 ± 10	
BMI (mean ± SD)	24.5 ± 4	26 ± 8.1	
Weight (mean ± SD)	74.1 ± 14.2	76.4 ± 18.9	

Table 3 One year characteristics of LWD group and Conventional treatment groups

	LWD RBH n=31	CON RBH n=10	CON PGH n=28
Age (mean ± SD)	N/A	N/A	
HbA1c (mean ± SD)	7.6 ± 1.3	8.9 ± 2.8	8.25 ± 2.3
Systolic BP (mean ± SD)	140 ± 19	128 ± 5.7	
Diastolic BP (mean ± SD)	83 ± 9.3	73 ± 8	
BMI (mean ± SD)	26.5 ± 4.1	28.6 ± 8.8	
Weight (mean ± SD)	80.2 ± 16	87.4 ± 15.5	

Table 4 Change in HbA1c for the LWD group

	LWD	Conventional
Baseline HbA1c	11.6 ± 2.1	11.4 ± 3.3
HbA1c at 3 months	7.5 ± 1.2	
HbA1c at 6 months	6.9 ±1.1	
HbA1c at 1 year	7.6 ± 1.3	8.9 ± 2.7

4.3.1.2 Psychological screening questionnaire results for LWD group

The scores for the PAID and HADS questionnaire for the LWD group at baseline, 3 months, 6 months and 1 year are shown in tables 4 and 5. Paired t-tests were used to determine whether there were significant changes in psychological scores between the two groups. A significant increase (p=0.041) was seen in the PAID emotions score at 6 months but significant decreases in PAID food (p=0.01) and PAID total (p=0.025) scores were seen at 6 months. However there were no significant changes between 3 month PAID scores and 12 month scores. Table 3 shows the HADS scores over the year. All HADS scores improved at 12 months after the diagnosis. However this was not a significant change.

Table 5 PAID scores for the LWD group

	Emotions	Treatment	Food	Social	Total
3 months	8.7±7.7	0.89±1.7	2.9±2.2	0.5±0.9	13.3±10.1
6 months	9.3±6.9	0.73±1.2	2.1±2.3	0.4±0.9	12.9±9.7
9 months	9.4±8.4	0.79±1.42	2.4±2.3	0.6±1.4	13.1±13
12 months	7.3±4	0.56±1.3	1.3±1.5	0.4±0.7	9.7±6.8

Table 5 HAD scores for LWD group

Time	Anxiety	Depression
3 months	5.5±2.9	2.0±1.2
6 months	4.5±2.9	2.3±2.3
9 months	5.5±4.2	2.36±2.2
12 months	3.0±1.5	1.7±0.8

4.3.1.3 HbA1c and Psychological screening questionnaires and results

Bivariate correlations were carried out to determine the relationship between the HbA1c and psychosocial distress in patients who attended the LWD programme. There was a negative correlation with baseline HbA1c and baseline emotional distress levels (r=-.521;p=0.047) as well as baseline PAID total scores (r=-0.542;p=0.037) suggesting that patients with a higher HbA1c at baseline had lower psychological distress levels. There were no significant correlations between HbA1c at 1 year and baseline scores.

HbA1c at one year was positively correlated with PAID treatment scores (r=0.825;p=0.006) suggesting that participants with lower treatment scores were more likely to have a lower HbA1c at one year.

There were no associations between HbA1c at one year and the change in psychological scores, or between the change in HbA1c and baselines scores.

The change in HbA1c was negatively correlated with emotional distress at one year (r=-0.774;p=0.24), negatively correlated with PAID food (r=-.797;p=0.018) and PAID total scores (r=-.795;p=0.018). This suggests that patients who have lower emotional distress levels, less food-related issues and lower total PAID scores had more improvements in HbA1c.

There were no associations between the change in HbA1c and the change in psychological scores.

4.3.2 Assessing the benefits of the LWD programme using qualitative interviews.

4.3.2.1 Biomedical and Psychological Data for interviewed patients

28 patients were diagnosed with type 1 diabetes at Poole General Hospital (PGH) between January 2004 and June 2005. 5 patients consented to participate in the study from PGH. 31 patients attended the newly-diagnosed programme at the Royal Bournemouth Hospital and 10 of these patients consented to participate in the study. The baseline biomedical data of the RBH and PGH patients can be found in table 6. Baseline psychological data (table 7) is only available for RBH patients who attended the LWD programme. The psychological scores at one year for both groups of patients can be found in table 8. The improvement in HbA1c is significantly better in the LWD group who were interviewed.

Table 6 Baseline characteristics and HbA1c levels for the interviewed patients at RBH and PGH

	RBH n=10	PGH n=4
Age (mean ± SD)	45.4 ± 14.1	43.2 ± 3.27
Gender	50% male	75% male
Smoker	Non-smoker 90%	Non-smoker 75%
HbA1c at baseline (mean ± SD)	12.6 ± 1.5	10.6 ± 2
HbA1c at one year (mean ± SD)	7.2 ± 6.7	8.1 ± 2

Table 7 Psychological scores at baseline of interviewed patients attending LWD programme at Royal Bournemouth Hospital (mean ± SD)

PAID					HADS	
Emotion	Treatment	Food	Social	Total	Anxiety	Dep
14.3 ± 10.5	0.6 ± 0.5	3.1 ± 3.4	0.72±1.1	18.7±13.5	6 ± 2.3	3.2 ± 2.6

Table 8 One year psychological scores of Poole patients and RBH patients

	CIDS	PAID					HADS	
		Emotion	Treatment	Food	Social	Total	Anx	Dep
RBH n=10	95.3±9.2	6±3.8	0.1±0.3	0.8±1.3	0.1±0.3	7.1±5.1	2.8±2.2	1.6±1.2
PGH n=5	94±12.2	10±12.8	1.7±1.7	2.7±3.8	0	14±18.4	4.7±5.2	6.3±9

There were significant differences compared to baseline for emotional responses on the PAID questionnaire and total PAID scores ($p=0.05$) in the Bournemouth group of patients who had attended the LWD programme. There was a significant difference between the two groups at one year for treatment scores on the PAID questionnaire. The transcripts were analysed and five themes emerged. These are Adjustment, Freedom, Support, Control and Knowledge.

4.3.2.2 Transcript analysis

Theme 1. Adjustment

As with many individuals with diabetes, the participants completing the newly diagnosed programme commented on the difficult time they had at diagnosis and the distress at receiving the diagnosis. The early months after diagnosis were daunting. However they all felt that a year later they were coping well and coming to terms with the diagnosis. Some of the individuals felt that they had learnt to make the necessary changes to their lifestyle so that they could live as normal life as possible alongside the diabetes.

'It is not the norm. All things have to change, you have to adapt to that day or that week. But all the time it is 'right this is something I do every day' you almost forget about it.' (R4, male)

Individuals who received conventional treatment were more likely to comment on the difficulties they were facing and the day-to-day problems which occurred. For one person this resulted in feelings of depression.

'Just existing but no life. It is just existing for the shear hell of it. That's what it means to me.' (R11, male)

Theme 2. Freedom

Carbohydrate counting allows patients to have dietary freedom and good glycaemic control. All patients who had attended the LWD programme felt that they could eat what they wanted and there were no restrictions to their diet and consequently there were no restrictions to their life. This contributed to the ease with which they were able to cope with the diabetes.

'I can eat normally within reason like anybody should do to look after their health.' (R4, male).

Patients who received conventional treatment had been taught some of the principles of carbohydrate counting although they had not formally attended an education programme. These individuals did not comment on the freedom or flexibility that can be associated with this.

Theme 3. Control.

The participants were not afraid to make changes to their diabetes regimes and were able to adjust their insulin appropriately to the situation. They were able to explore the causes for hypo- or hyperglycaemic episodes and react to them with the most appropriate treatment. As a result they felt in control of their diabetes and had no fear of hypoglycaemia. All participants had concerns about long-term complications. However they also felt that they had the ability to control their diabetes and reduce the risks of complications in the future. The individuals involved in the study were targeting good control and felt this was not only achievable but possible to maintain.

'When I am swimming I have got the confidence to change things. I know what to do when I am high. I know I come down by doing extra insulin, how to calculate carbohydrates. I don't have a problem.' (R1, female)

Participants in the study who had conventional treatment were more likely to describe periods of poor control. This often resulted in feelings of frustration and worries about long-term complications.

'*I had a bad cold and I changed jobs all within two weeks and suddenly my diabetes went out of control… no matter what I seemed to do I just couldn't get it back in control and I got very frustrated with it. I almost got quite low over it that. Suddenly I had this thing that no matter what I do, I cannot seem to get this right.'* (R13, male)

Theme 4. Support

There are two aspects to this theme. These were peer support and the support from health care professionals. Participants felt that they were able to learn from other patients' experiences and solve their problems in the small group discussions. The individuals believed that their experiences were more likely to be acknowledged and validated by other patients compared with health care professionals. The programme was also thought to be an 'open forum' and as such allowed the patients' agenda to be followed rather than that of the healthcare professionals. Participants also felt that this forum allowed all their questions to be answered over the year.

'..very helpful because you also come along to these classes and meet people who have had it for longer and you think how well they have coped with it. I have learnt a lot from them. They would say how they felt and I would think, oh yes, that's me.'
(R1, female)

All participants who had conventional treatment, felt that they had received good support from all healthcare professionals at diagnosis. However they were more likely to describe problems which occurred at least six months at diagnosis and it was at this point that they felt that less support was available.

'I felt that over time somebody who would teach me a bit more and then I went to my first six-monthly check-up, expecting for people to say right now we will teach you the next bit and nobody did so when it started going wrong, yes I did make a few phone calls, yes people did call me back and say we'll try this we'll try that and see if it works but nobody has actually educated me on diabetes.' (R15, male).

Theme 5. Knowledge

All participants thought that they had developed a good knowledge and understanding of the key diabetes issues over the year. They had felt that it can be difficult to take in some of the facts shortly after diagnosis. However the sessions took place over the year and that allowed participants to accumulate that knowledge at their own pace.

‘I have not come across anything which I think, I wonder why nobody told me about that, because we have had three-monthly mornings – you have got every opportunity to get all the information that you think you might want.’ (R5, male)

4.4 Discussion

The results showed that patients who attended the Living with Diabetes programme had a similar baseline HbA1c to those who had conventional treatment at Royal Bournemouth Hospital. The LWD group did however have a mean HbA1c that was 1.3% lower than the conventional group at 1 year although this was not significantly different. This may reflect the difference in the sample size of the two groups. The LWD group had a lower weight at baseline and 1 year although this was not significant and both systolic and diastolic BP were significantly higher ($p=0.037$ and $p=0.021$ respectively) in the LWD group. Emotional distress scores were significantly higher at six months and this suggests that the more challenging time for patients is at six months rather than earlier after diagnosis which traditionally represented the time of most intensive support. The correlation analyses demonstrated that patients with a higher HbA1c at baseline had lower levels of psychological distress at baseline which may suggest that patients early on at diagnosis may not be as emotionally distressed at that time. At one year patients who have better glycaemic control tend to have lower total PAID scores and therefore less diabetes distress.

The emerging themes from the interview subjects suggest that participants of the newly-diagnosed programme for type 1 diabetes may benefit in a number of ways. Participants were more likely to comment that they had coped well with the diagnosis and had made the necessary adjustments to their lifestyle in order to cope with the diagnosis and management of their diabetes. They also felt that the diagnosis of diabetes did not preclude a normal lifestyle although extra planning may be required. Perhaps more importantly the patients felt in control of their diabetes and had developed problem-solving abilities which had helped them to deal with difficult management situations. These themes suggest that this group of patients had accepted their diagnosis and as a result were better able to self-manage their diabetes. Patients who had conventional treatment were more likely to express frustrations with their diabetes management. They all felt well supported by health care professionals at the time of diagnosis when contact was frequent. The frustration was felt at a later date when the ‘novelty’ of the diagnosis had gone and glycaemic control was becoming more of a problem. At this point contact with healthcare professionals was infrequent and this suggests that patients need ongoing support over the year. The newly-diagnosed programme takes place every three months and allows the patient to maintain contact with all members of the multidisciplinary team at a time when regular appointments and telephone calls would previously have ended. The sessions also give patients an opportunity to explore with their peers any difficulties that they may be having. Individuals with diabetes are more likely to trust problem-solving ideas and behavioural changes from other people with diabetes rather than healthcare professionals. It is also difficult for some patients to take in the vast amount of information at diagnosis. Regular meetings also give the participants sufficient opportunity to obtain answers to some of their questions and problems.

The psychological scores suggest that treatment scores (and therefore total scores) for the PAID questionnaire as well as HADS anxiety scores improve significantly following the newly-diagnosed programme. The improvement in anxiety scores suggests that the anxiety felt at diagnosis may largely be related to treatment issues and ‘diabetes-related distress’ which improved as the participants felt more confident with their management skills.

The limitation however is the small sample size. The response rate for patients who had conventional treatment at Poole Hospital was poor and this reduced the effective sample size and will have introduced some bias. Follow-up letters to the initial invitations were sent but this did not improve the response rate. This may have also affected the psychological scores and further studies with a larger size are needed to confirm these results. The information from these interviews is also limited but does suggest that patients who complete the newly diagnosed programme have accepted their diagnosis better and have developed good self-management skills and that the programme provided ongoing support when psychological distress became more prominent. The levels of self-efficacy in both groups are similar and it would be difficult to make a comparison given the small number of participants. .

There are a number of challenges for the future and more research is needed to confirm the impact of the programme on people with newly-diagnosed diabetes. A study with more participants assessing the impact on glycaemic control and levels of psychological distress one year after diagnosis and in the longer term is needed and the results should be compared with patients who have had conventional treatment. However it might be considered inappropriate to carry out a randomised control trial and withhold the programme from some newly-diagnosed individuals. A small number of patients did not attend the programme. There may be a number of reasons for this. The programme was voluntary and some patients may have preferred individual appointments rather than a group programme or they may not have received an invitation at their nurse appointment. Some individuals may have suffered with psychosocial distress related to other problems which prevented their attendance. This could be a problem for a randomised control trial as the patients with significant psychosocial distress may not volunteer for randomised control trials for programmes such as the newly-diagnosed programme.

This study demonstrates that the LWD programme provides a number of benefits for people with newly-diagnosed type 1 diabetes. The programme provides peer support for patients which can improve problem-solving and self-management skills. Emotional distress is higher at 6 months after diagnosis compared with the score at 3 months and this programme provides better structured support from healthcare professionals at this time.

5 Intensive Education

5.1 Introduction

The most well-known structured education programme for people with type 1 diabetes was initially developed in Düsseldorf.[23] Many other European structured education programmes have been based on the Düsseldorf programme. These programmes have been shown to consistently improve glycaemic control in individuals without increasing hypoglycaemia.[22;25] Structured education has increasingly become an integral part of the routine management for people with type 1 diabetes in the UK.[141] Both the Bournemouth Type 1 Intensive Education programme (BERTIE) and the Dose adjustment for Normal Eating programme (DAFNE) are based on the Düsseldorf programme[21;36] and a number of centres in the UK have based their programmes on either BERTIE and DAFNE.[141] The Düsseldorf programme has shown that glycaemic control can not only be improved with structured education but that this improvement can be maintained for up to four years after the programme.[26]

The Bournemouth Type 1 Intensive Education programme is run 1 day a week for 4 consecutive weeks. The programme covers carbohydrate counting, insulin dose adjustment, correction doses as well as the effects of exercise and alcohol on glycaemic control. Patients are invited to participate in the programme, through clinic and diabetes specialist nurse appointments, and to date 304 patients have completed the programme. The programme is open to all patients with type 1 diabetes and there are no exclusion criteria.

The data from the DAFNE programme in the UK has shown that improvements in HbA1c of 0.36% can be seen four years after the programme was carried out in routine practice.[142] More recent data has demonstrated that high levels of psychological distress improved one year after the programme.[143] The aim of this project was to evaluate the effect on glycaemic control in individuals four years after participation in the Bournemouth education programme and also to determine what happens to psychological distress levels after intensive education and the relationship with HbA1c.

5.2 Methods

5.2.1 Intervention

The Bournemouth Type 1 Intensive Education Programme consists of four sessions over four consecutive weeks. Each session lasts for 6 hours. Patients are referred to the programme by diabetes physicians and diabetes specialist nurses and an increasing proportion of patients are referred from out of area diabetes physicians. 6 to 8 patients participate on each programme. The programme is delivered in a community centre away from the hospital and facilitated by a diabetes specialist nurse and dietitian; a diabetes physician and psychologist attend some sessions on weeks 1 and 4. The programme provides both individual and small group teaching which aims to be interactive and patient-centred. Participants are encouraged to reflect, share their experiences and to ask any questions. The facilitators aim to answer all questions in an honest, open and non-judgmental way. A complete timetable is found in appendix 5 and the learning objectives and sample lesson plans for the introduction to carbohydrate counting and the psychology session can be found in appendices 6 and 7. This education programme, like the LWD programme was based on Bandura's social learning theory.[99] A buffet meal is provided in the first three weeks and this gives participants the opportunity to practise carbohydrate counting and insulin dose adjustment. Participants are encouraged to practise carbohydrate counting and insulin dose adjustment over the coming week before the next session.

5.2.1.1 Week 1

Initial discussions focus on introductions and goal setting. Goal setting is an important component of the programme. The theory of goal-setting has developed over the last four decades[144]and is based on the principle that conscious goals will have an effect on an action to a specific standard and within a defined time limit[145]. There is some evidence to suggest that goal setting can help individuals initiate and maintain new behaviours in a variety of different situations.[144] Individuals who set themselves challenging goals are also more likely to achieve success particularly if these goals are set by the individuals rather than a health care professional.[144] However feedback and support on goal progression is also necessary in order to help individuals change their behaviour. Following the goal-setting patients are given a workbook which can be used in conjunction with the interactive sessions. During this session patients learn about diabetes, the actions of insulin, and the role of blood glucose monitoring. Carbohydrate counting (appendix 6) is introduced in an interactive workshop and patients are guided towards the use of an insulin to carbohydrate ratio. Participants are shown how to use blood glucose testing to make self-management decisions. They are encouraged to use carbohydrate (CP) reference tables and the type 1 handbook and to make notes throughout the programme.

5.2.1.2 Week 2

This session begins with feedback about patients' experiences over the last week and a review of individual goals. This is followed by a further session on assessing carbohydrate content of foods, and then a discussion about hypoglycaemia. The participants are actively engaged by asking them specific questions about their experience of hypoglycaemia, followed by discussion on the symptoms of hypoglycaemia, its causes and also the most appropriate treatment. This is followed by a session on the effects of exercise on blood glucose levels. The facilitator aims to increase understanding of the management of insulin and food with exercise, the replenishment of energy stores and measurement of ketones prior to exercise. Participants are encouraged to engage in physical exercise during the following week and to monitor glucose levels before and afterwards.

5.2.1.3 Week 3

Week 3 again starts with a feedback session. This is followed by a discussion on the symptoms and causes of hyperglycaemia and the signs and treatment of diabetic ketoacidosis. Advice on how to manage hyperglycaemia with correction doses of insulin is also given. There are two nutrition sessions which focus on the difficulties of eating out and estimating the carbohydrate content of takeaways and the effect of alcohol on blood glucose levels. Patients are asked specific questions to help them reflect on their experiences when eating out. Discussions on the challenges of counting the carbohydrate in food acquired away from home are held. Participants are also asked to reflect on their previous experience (if relevant) of drinking alcoholic drinks. The educator facilitates an interactive workshop using drinks models. Any participant who does not feel this session is relevant is welcome to sit out of the session.

5.2.1.4 Week 4

Week 4 begins with feedback from the participants' experiences and a final review of personal goals. This is followed by a discussion concentrating on the signs, symptoms and treatments of microvascular and macrovascular complications of type 1 diabetes. Specific questions are used to elicit prior knowledge in order to help participants to reflect on prior experience. It is recognised that complications of diabetes can be severe but the emphasis is that the vast majority can be screened for and treated to avoid long-term consequences. An interactive discussion on the psychological aspects (appendix 6) ensues. The psychologist invites the participants to reflect on the interaction between their thoughts, feelings and behaviour. Illustrations of helpful and unhelpful interactions are used to explain vicious circles and barriers to self management. The participants are encouraged to reflect and share experiences. There is a final session on carbohydrate estimation and a session on reflection and evaluation followed by a meal out with the whole team.

5.2.2 Intensive Education and Glycaemic Control

Biomedical data such as HbA1c, weight, duration of diabetes and smoking history are collected prior to the programme. A register of all patients who have completed the programme is kept at the Bournemouth Diabetes and Endocrine Centre. Participants are sent forms to have a blood test for an HBA1c measurement at 3 months and 6 months. The register is updated with HbA1c measurements on a yearly basis using data from clinic appointments. Individuals who attended the education programme between 1999 and 2003 were identified from the register.

5.2.2.1 Statistical analysis

Analysis of the data was undertaken with SPSS using paired t-tests to compare baseline variables with levels at 3 and 6 months, 1, 2, 3 and 4 years. Independent t-tests and bivariate correlations were used to determine whether baseline variables (weight, duration of diabetes, smoking, gender and previous carbohydrate counting experience) were associated with the change in HbA1c. Scatter plot graphs were used to determine the relationship between any positive or negative correlations.

5.2.3 Intensive Education and Psychological Distress

Three psychological screening questionnaires are collected prior to the intensive education program. These are the Diabetes Health Profile (DHP)[122], the Hospital Anxiety and Depression Questionnaire and the Rosenberg Self-esteem Scale[126]. All patients who attended the intensive education programme during 2002 and 2003 (n=59) were invited to participate by letter one year after they had been on the intensive education programme. They were asked to attend an evening session in the Diabetes Centre where they completed the three questionnaires. A blood sample was also taken for an HbA1c measurement.

5.2.3.1 Statistical Analysis

Psychological scores at baseline were compared with one year scores using paired t tests. The change in HbA1c was correlated with baseline and one year psychological scores as well as the change in psychological scores. Patients who attended the education programme within a year of diagnosis were analysed separately as they may have been going through a ‘honeymoon period’. A ‘honeymoon period’ is the transient improvement in glycaemic control and endogenous insulin production often seen in newly-diagnosed patients following the start of insulin treatment. Therefore any improvement in glycaemic control in this group of patients may be a result of the honeymoon phase rather than the education programme and so a separate analysis was carried out.

5.3 Results

5.3.1 Intensive Education and Glycaemic Control

121 patients attended the intensive education programme at the Royal Bournemouth Hospital between 1999 and 2003. 9 patients attended the education programme within a year of diagnosis. One patient was excluded as he only attended the first session. Table 9 shows the baseline characteristics of the patients who attended intensive education between 1999 and 2003. Figure 1 shows the change in HbA1c over 4 years. Significant improvements in HbA1c were seen at 3 months ($p<0.001$), 6 months ($p<0.001$), 1 year ($p=0.036$), 2 years ($p=0.036$), 3 years ($p=0.01$) and 4 years ($p=0.012$) compared with baseline compared with baseline HbA1c.

Table 9 Baseline and 1 yr characteristics n=111

Age (Mean ± SD)	37.2 ± 13.7
Duration of diabetes (Mean ± SD)	13.7 ± 12.2
HbA1c Baseline (Mean ± SD)	9.3 ± 1.2
HbA1c at 1 yr (Mean ± SD)	8.8 ± 1.2
Baseline weight (Mean ± SD)	75.5 ± 13.7
Weight at 1 yr (Mean ± SD)	74.7 ± 13.1
Baseline BMI (Mean ± SD)	25.9 ± 3.9
Smokers (%)	19
Male participants (%)	56

Figure 2 shows glycaemic control for patients who had previous experience of carbohydrate counting (prior to 1992 or since 2001) and patients who had no previous experience of carbohydrate counting until the intensive education programme.

Figure 1 Change in HbA1c over 4 years

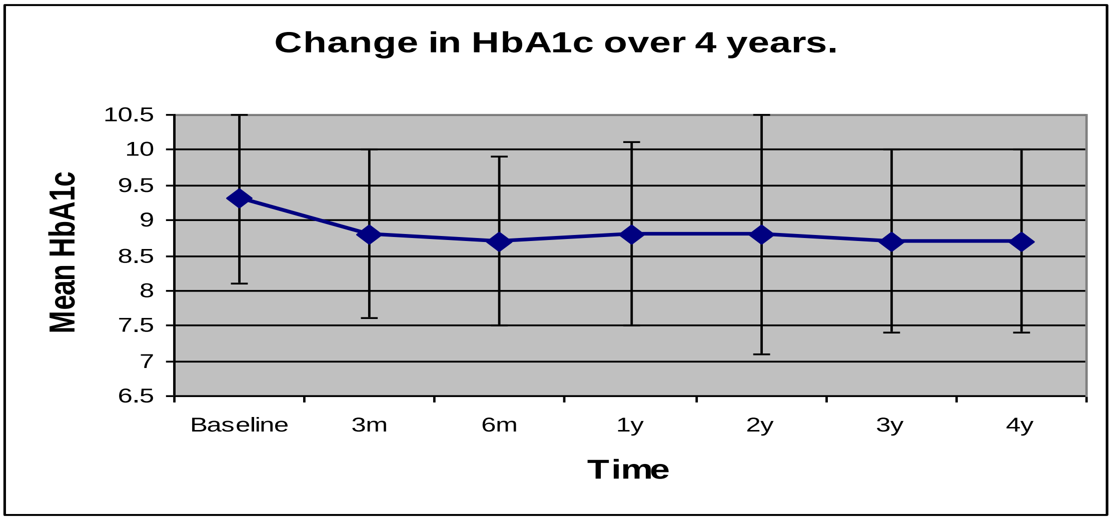
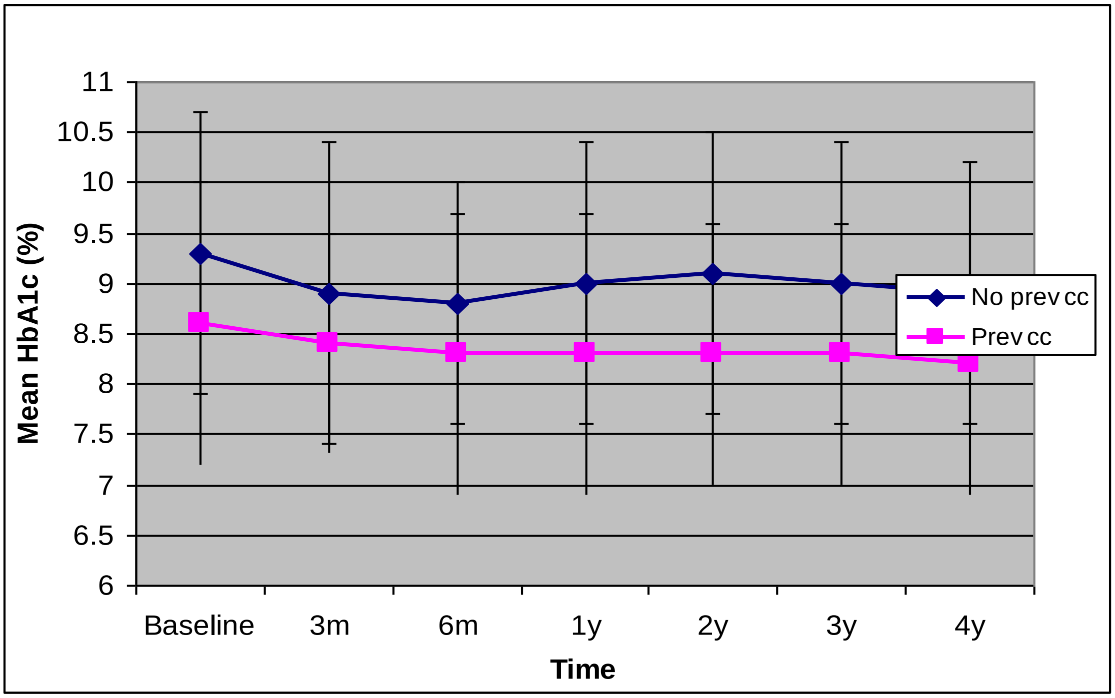


Figure 2 Carbohydrate counting experience and HbA1c



There were significant differences between the two groups at baseline (p=0.007), 1 year (p=0.014), 2years (p=0.004) and 4 years (p=0.014). However independent t-tests on the change in HbA1c levels at any point were not significantly different, suggesting that the differences were related to the difference in mean score from baseline.

There was no significant difference in HbA1c at baseline, 3m, 6m, 1y, 2y, 3y and 4y for smokers and non-smokers.

Correlations analyses were used to look at the change in HbA1c at 1 year and baseline variables. They demonstrated a negative correlation between the change in weight and the change in HbA1c at one year (r = -0.489, p<0.001) suggesting that patients with higher weights at 1 year have lower HbA1c levels.

There were no correlations between duration of diabetes, age, smoking history and the change in HbA1c at 2, 3 and 4 years from baseline. Therefore multiple regression analysis was not possible. Independent t-tests did however demonstrate significant differences between male and female participants at 2 years (p=0.029), 3years (p=0.045) and 4 years (p=0.008) (figure 3).

Figure 3 Gender and change in HbA1c

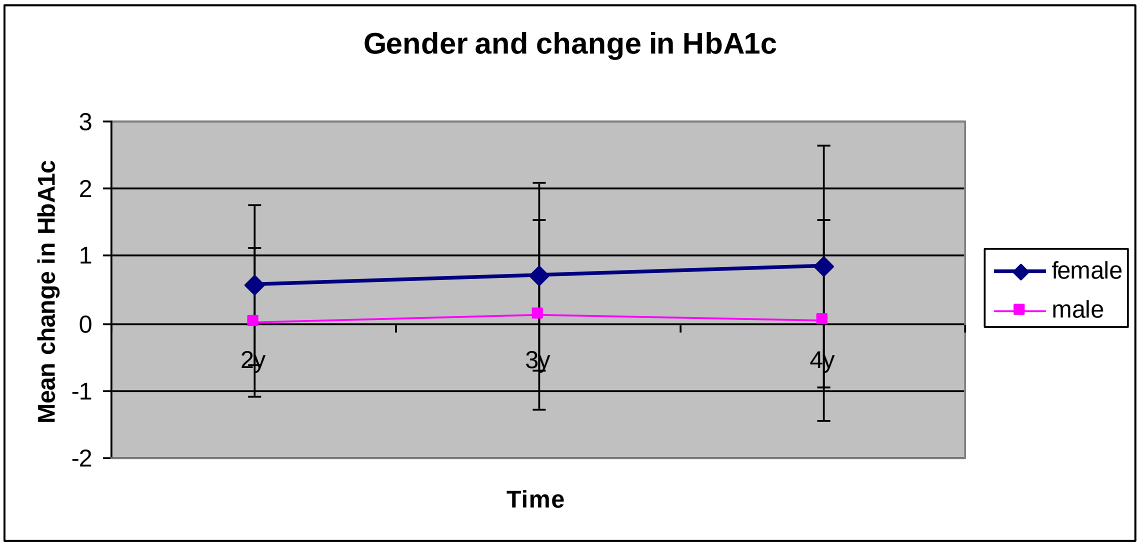
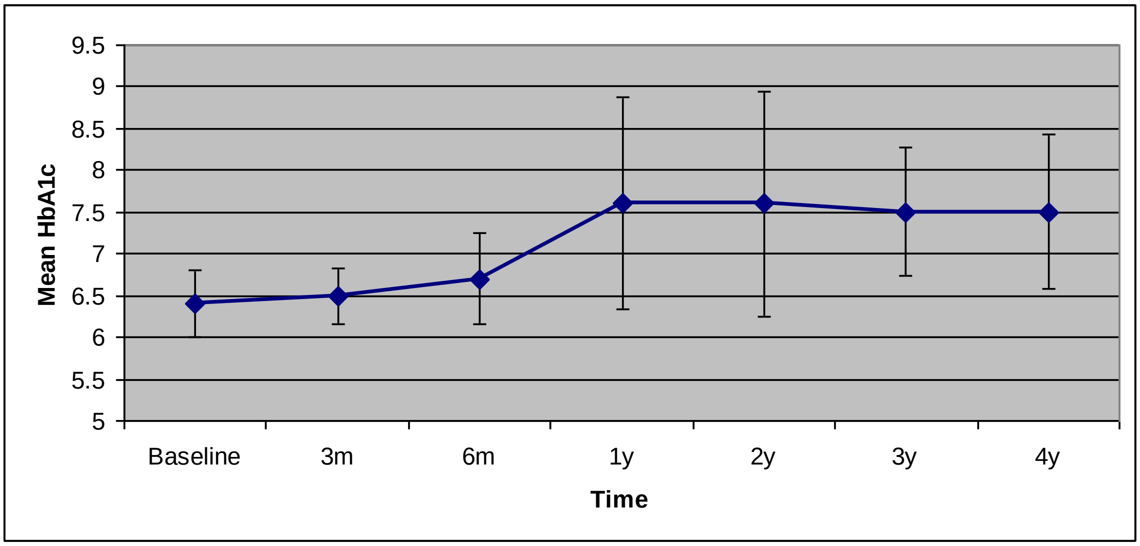


Table 10 shows the baseline and one year characteristics of the patients in the 'honeymoon' period and Figure 4 shows the change in HbA1c over 4 years. There are significant increases in the mean HbA1c from baseline at 1 year (p=0.043), 2 years (p=0.056), 3 years (0.006) and (p=0.032).

Table 10 Baseline and 1 year characteristics of patients with diabetes duration <1 year at education (n=9)

Age (Mean ± SD)	38.9 ± 13.5
Duration of diabetes (Mean ± SD)	.55 ± 0.2
Baseline HbA1c (Mean ± SD)	6.4 ± .4
Baseline weight (Mean ± SD)	74 ± 14.7
Baseline BMI (Mean ± SD)	25.3 ±3.9
Smokers (%)	56%
Male participants (%)	56%
HbA1c 1year	7.6 ± 1.27
Weight at 1yr (Mean ± SD)	79.9 ± 13.8

Figure 4 Change in HbA1c for patients with diabetes duration <1 year at education (n=9)



5.3.2 Intensive Education and Psychological Distress

Table 11 shows baseline and one year score for the three psychological screening questionnaires Diabetes Health Profile (DHP), Hospital Anxiety and Depression (HADS), Rosenberg Self-esteem Scale (RSE) and HbA1c. 30 patients participated in the study. However baseline psychological data was unfortunately missing from the files for 10 patients and therefore it was not possible to include these patients in the analysis.

Table 11 Baseline and one year scores

	DHP			HADS		RSE	HbA1c
	Psych. Distress	Barriers to Activity	Disordered Eating	Anxiety	Depression		
Mean Scores Baseline	5.6 ± 4.2	7.1 ± 5.8	4.4 ± 2.4	5.0±4.6	3.5 ± 4.4	15.7± 7.9	8.5 ± 4.9
Mean scores 1year	6.0 ± 5.2	6.5 ± 4.2	3.8 ± 2.4	5.517	2.8 ± 2.9	17.5 ± 4.7	8.5 ± 1.3
Mean change	-0.35 ± 3.1	0 ± 3.0	0.3 ± 1.6	0.05 ± 5.3	0.3 ± 1.6	0.7 ± 9.5	0.01 ± 1.0

Correlation tests were used to determine the associations between baseline HbA1c, one year HbA1c and the change in HbA1c levels with psychological scores before and after education.

There were no significant correlations between baseline HbA1c and baseline psychological scores

One year HbA1c was positively correlated with baseline disordered eating scores (r=0.447;p=0.048) and suggesting that participants with lower disordered eating levels at baseline had lower HbA1c levels after education. One year HbA1c levels were positively correlated with psychological distress (r=0.447;p=0.015), disordered eating (r=0.420;p=0.023) and depression (r=0.407;p=0.029) at one year suggesting that patients with a lower HbA1c after education were those with lower psychological distress, less disordered eating and lower depression levels.

The change in HbA1c was positively correlated with the change in psychological distress (r=0.0463;p=0.04) and with the change in anxiety (r=0.494;p=0.023) but negatively correlated to the change in barriers to activity (r=-0.474;p=0.035) and baseline barriers to activity (r=0.652;p<0.002). This suggested that participants who improved their HbA1c were more likely to have improved their levels of psychological distress and anxiety levels and were perhaps those who did not perceive barriers to normal activity before they completed the programme.

5.4 Conclusion

This study demonstrates that patients who complete the Bournemouth Intensive education programme can improve their HbA1c by 0.5% and maintain this improvement in glycaemic control for four years. Overall this was not associated with a change in weight although there was an association between weight gain and lower HbA1c at 1 year. Duration of diabetes, age and smoking history had no bearing on the change in HbA1c over four years suggesting that the programme is beneficial to patients at any time and no one should be excluded. Carbohydrate counting in the form of fixed insulin doses and carbohydrate lines was a routine part of diabetes education before 1992. However a British Dietetic Association document produced in 1992 encouraged dietary freedom and many patients diagnosed with type 1 diabetes were given insulin regimes which included fixed doses of insulin with meals and no information on carbohydrate content. In Bournemouth, patients diagnosed after 2001 however, were taught basic carbohydrate counting from diagnosis. Patients who were diagnosed before 1992 or after 2001 did not have more significant changes in glycaemic control following education. However they did have better glycaemic control at baseline. This emphasises the importance of understanding the role of carbohydrates in achieving better control of diabetes and that patients with more experience of carbohydrate counting may do better.

The improvements in glycaemic control are comparable to DAFNE data which demonstrated an improvement of 0.36% at four years,[142] and the Düsseldorf programme where a 0.6% improvement occurred at 4 years.[146]

The second part of the study looked at psychological distress and glycaemic control. There were no significant improvements in mean psychological scores one year after the education programme. The results did highlight that patients with less eating difficulties at baseline are more likely to improve their glycaemic control one year after intensive education. Participants who improve their glycaemic control following intensive education are more likely to reduce their levels of psychological distress, disordered eating and depression. The sample size is small and limited by the lack of baseline data for some patients; participants were recruited by letter which may have limited the response to the study. It was not possible to extend the study as baseline questionnaires for the education programme had been changed to the PAID[71] questionnaire which was considered a better measure of psychological distress compared with the Diabetes Health Profile.

There are a number of patients who do not improve their glycaemic control after completing the education programme. The challenge is to identify the causes for the lack of improvement in some individuals and determine which aspects of the programme could be improved. Literacy and numeracy skills may also be a barrier for some patients. Individuals with poor literacy skills may have difficulty following medical advice as well as performing self-management skills[147]. Good numeracy skills are required to interpret blood glucose levels and calculate insulin doses; this is an essential part of intensive insulin therapy and poor numeracy skills may affect individuals' response to the education programme. Psychological distress may also be a barrier to improvement in glycaemic control. Patients who suffer with anxiety and depressive symptoms as a result of poor diabetes control may find that intensive education can alleviate some of these symptoms. However patients who experience psychological distress unrelated to their diabetes may need more specific psychological therapy before attending the education programme.

In conclusion, the Bournemouth Type 1 Education programme has shown significant improvements in glycaemic control for a number of patients but a number of barriers may prevent improvement in some individuals. It is essential that we determine those barriers in order to maximize the benefit of our education programmes.

6 Structured Education: Why does it not work for everybody with type 1 diabetes?

6.1 Introduction

The Bournemouth Type 1 Intensive Education programme (BERTIE) [148] aims to promote self-management skills through increasing knowledge on carbohydrate counting and insulin dose adjustment as well as the correct treatment of hypo and hyperglycaemia and the effects of alcohol, exercise and other lifestyle factors on blood glucose levels. People completing the BERTIE programme, show a mean reduction in HbA1c of 0.5%, which is maintained for up to 4 years. Whilst most participants showed improvements in self-management skills, not all patients improved their glycaemic control after attending the education programme. More detailed evaluation of the programme has suggested that 24% of participants remained within 0.5% of their baseline HbA1c after education, and glycaemic control deteriorated by at least 0.5% from baseline in 10% of participants. These results are not dissimilar to the Düsseldorf programme, which found that about one third of participants failed to achieve their therapeutic targets and required further structured education.[149] The Düsseldorf group has endeavoured to identify the predictors of glycaemic control following an education programme.[150] Although diabetes-related knowledge was the most highly correlated with glycaemic control, smoking was found to be the most consistent predictor of glycaemic control. However, the variation for a significant number of HbA1c values was unexplained, suggesting that other unidentified variables are also involved. A specific five-day inpatient programme for this group of patients, was developed by the Düsseldorf group but they were unable to demonstrate a further improvement in HbA1c following the programme despite improvements in hypoglycaemia.[151] A meta-analysis using 42 studies, from Anderson in 2001, estimated that the risk of depression in people with diabetes is nearly trebled.[152] Depression is associated with hyperglycaemia[153] and untreated may also be a barrier to improving glycaemic control after structured education. Treatment of psychological difficulties has also been shown to result in sustained changes in glycaemic control.[154] In order to improve the efficacy of our education programme, it is necessary to understand why some patients do not improve their glycaemic control following structured education. The aim of the study was to identify any issues from the patients' perspective that inhibit an improvement. The findings could then be used to revise the education programme to respond to patients' needs more effectively.

6.2 Methods

6.2.1 Study design

A qualitative study using single semi-structured interviews allowed an in-depth exploration of the issues which might affect patient responses to structured education. Psychological screening questionnaires were completed by patients together with demographic data, to provide further information on study subjects.

6.2.2 Participants and recruitment

Patients with type 1 diabetes, who had attended the Bournemouth education programme between 2001 and 2003, were recruited. Participants were divided into two groups: those who improved their glycaemic control by more than 0.5% at one year after the programme were defined as positive responders and patients who improved their glycaemic control by less than 0.5% were defined as negative responders.[155] In total there were twenty-five negative responders and twenty-seven positive responders. Fifteen participants were recruited by letter, and four participants were recruited whilst attending the Diabetes Centre for a Nurse Specialist consultation. Ten participants in the negative responder group and 9 in the positive responder group were interviewed.

6.2.3 Data Collection

The semi-structured interviews explored the participants' views on the education programme and their diabetes management (appendix 8). The interviews were carried out at the Bournemouth Diabetes and Endocrine Centre or the participants' home and lasted on average 30 – 45 minutes. All patients provided written consent to participate and be tape-recorded. All transcripts, with analysis, were sent to the participants for validation.

6.2.3.1 Psychological screening questionnaires

The questionnaires used were the Diabetes Health Profile (DHP)[156] and the Hospital Anxiety and Depression Scale (HADS).[157]

6.2.3.2 Demographic Factors

Data was collected on age, sex, age at diabetes onset, diabetes duration, weight, alcohol intake, smoking status and HbA1c.

6.2.4 Data Analysis and Validation

The transcripts were evaluated using a thematic analysis with a data-driven approach.[158] The transcripts were reviewed and key words and phrases were highlighted. Themes were generated from the key words and phrases and a codebook describing the definition and indicators for each theme was developed. Team members reviewed the findings and reached agreement on all themes. The themes were subsequently compared between the two groups.

6.3 Results

There were no differences in age, duration of diabetes or weight between the negative responders and the positive responders (Table 12). Psychological screening scores for the DHP, HADS and RSE were not significantly different between the negative and positive responders either at baseline i.e. prior to the education programme or at one year following the programme (Table 13). Neither were there any significant differences between the groups at one year or more following the programme. However, at follow-up the trend towards improvement in the DHP scores was greater in the positive responders compared with the negative responders (Figure 5). The change in psychological distress was significantly different between the two groups at one year, the negative responders reporting increased distress compared with baseline. This pattern was also seen in the HADS, where the scores reflected a deterioration in the symptomatology of anxiety and depression in the negative responder group (Figure 6).

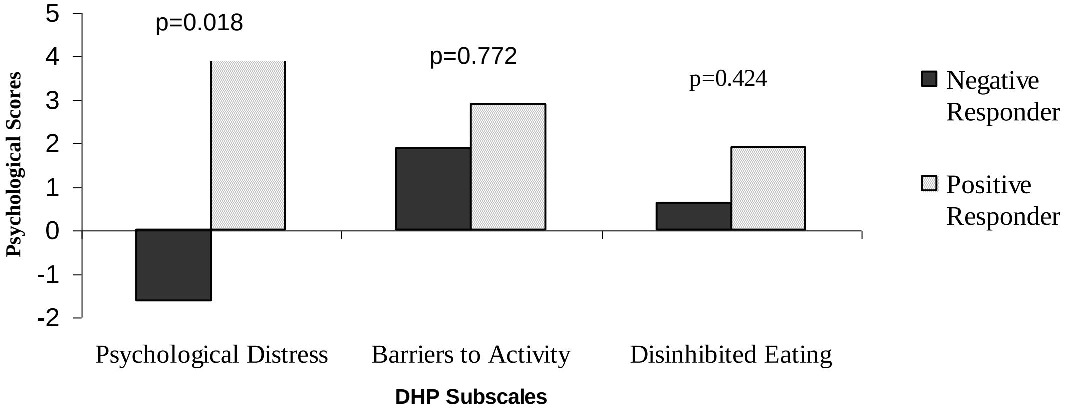
Table 12 Demographic profile of the negative and positive responders

Mean (sd)	Negative Responders n=10	Positive Responders n=9	p=
Number of patients	10	9	
Age (yrs)	44	37	0.26
Duration diabetes (yrs)	12	12	0.8
Weight (kg)	74	79	0.57
Baseline HbA1c (%)	8.5	9.5	0.01
HbA1c at 1 year (%)	9.6	8.0	0.004

Table 13 Psychological screening questionnaire scores

			Negative Responders	Positive Responders	p =
DHP	Psychological Distress	Baseline	5.7 ± 2.9	8.4 ± 6.6	0.63
		1 yr	7.7 ± 6.1	4.6 ± 3.0	0.28
	Barriers to Activity	Baseline	8.5 ± 6.5	9.7 ± 5.4	0.50
		1 yr	6.5 ± 4.8	6.8 ± 3.4	0.51
	Disinhibited Eating	Baseline	5.4 ± 4.1	5.6 ± 4.9	0.73
		1 yr	5.0 ± 4.1	3.7 ± 3.5	0.73
HADS	Anxiety	Baseline	3.0 ± 3.5	1.89 ± 2.1	0.37
		1 yr	4.3 ± 3.4	8.6 ± 6.8	0.30
	Depression	Baseline	5.7 ± 5.0	3.6 ± 4.2	0.53
		1 yr	2.9 ± 3.3	5.4 ± 6.3	0.56

Figure 5 Improvement in scores from baseline to 1 year for DHP



6.3.1 Emerging Themes

For many of the participants the intensive education programme was the first time they had met other people with diabetes. They reported having enjoyed the experience and felt less isolated with their condition. Five themes illustrate the differences in the perception of negative and positive responders about their diabetes and diabetes management. These themes are poor perception of diabetic control, accepting a chronic disease, negative thoughts, lack of motivation and lack of family support and are described in the following paragraphs.

Theme 1. Poor Perception of diabetic control

All patients were asked about their current diabetes control and their control prior to the education programme. The negative responders were more likely to express satisfaction with their control as illustrated by the following quotes.

'I would say it was good control day-to day and I certainly wasn't out of control and I wouldn't worry about it day-to-day.' (R4, female)

'Reasonable – it could be better, it could be worse.' (R5, male)

However, their HbA1c did not reflect these statements and both these patients had a value of 9% or above. This may reflect a poor understanding of the connection between HbA1c and acceptable levels of control or possibly denial that their control was poor. Positive responders generally conveyed a greater understanding and more concern if they had a high HbA1c. They also gave a more accurate assessment of their previous and current HbA1c levels and talked more about the blood sugar levels they were aiming for as illustrated below.

'My post-prandials were the ones that were really high and I couldn't get it back down and that was really because of what I was eating, so that was a bit of a struggle. My long-term test was about 7.5 – certainly in the first few years and then it was creeping up and up and it was above 10 and that scared me to death.' (R15, female)

'My control was pretty bad. I couldn't control it. It got to the stage when no matter how good I was being it just wasn't working. I can't remember what my HbA1c was but it was more than seven.' (R12, male)

Theme 2. Accepting a chronic disease

Being diagnosed with a chronic disease such as diabetes can have a huge impact on the individual. Patients often describe a reaction similar to being diagnosed with a terminal illness or going through bereavement. Individuals were not specifically asked about the time of their diagnosis, however negative responders often referred to difficulties and frustrations that they experienced at the time of diagnosis and how they had yet not come to terms with the diagnosis despite disease duration of several years.

'I do find being diabetic annoying and of course I have got no answers as to why I have got it. It is not in my family. My auntie only had type 2. The type I have happens in childhood or later on in life and I have got it at the age of 34 or whatever it was. That makes it more difficult to cope with. If someone could give me the answer as to why, but they can't give me an answer…I think why me, and why not my sister or my brother, you know, why me.' (R1, female)

Participants in the positive responder group would also describe the difficulties at diagnosis but were more likely to express views of acceptance.

'I got diabetes in 2000 and it was a bad time for me in my personal life and I think as a consequence of that my control started getting bad. My appetite was insatiable and I was eating like a horse and I had put on two stone and that made me more depressed and I was getting more and more into the doldrums…I have needed a lot of support and help from different people and again the different aspects – psychological, physical and the dietary side of it but at this stage I am feeling very positive and confident and leaps and bounds ahead of where I was a year ago.' (R6, female)

Theme 3. Negative thoughts

Participants, in the negative responder group, were more likely to express pessimistic thoughts about their diabetes control and management. They would see their diabetes management as frustrating or a struggle and lacked confidence to make changes to their management if they had had diabetes for a long time. This may be linked to their lack of acceptance.

'If I am high and I know that is because I am stressed, I will let it go for a couple of days. I get a bit like I can't be bothered, because I am sick of it and I am sick of having to look after it and it is wrong.' (R4, female)

'I am majorly pissed off with diabetes. I just think to myself – why won't it go away? I have been negative for a while. I have never been the sort of person who has really taken a great deal of care about myself anyway and now to add [diabetes] to it – it can make you feel miserable. There are so many things and processes that you have to go through to make you feel like a normal person.' (R9, female)

Negative responders also commented on complications in a more catastrophic manner e.g. they would be more likely to worry about gangrene, amputations and blindness.

However positive responders talked more about complications in a general manner or commented on specific problems such as wishing to avoid laser therapy. Positive responders also commented on difficulties that they had experienced. However, they also described how they had resolved and worked through their difficulties in order to feel more positive about themselves and their condition. They seemed to have accepted that diabetes was going to be a major part of their life but accepted the input required to manage their condition optimally in order to minimise the problems associated with it.

'When you are in the doldrums with diabetes – you have been doing it for yonks and you are not really getting anywhere and you are not sure what you are meant to be achieving anyway, you get depressed and think what does it matter – I can struggle through each day, I might not live as long as I might do if I was not diabetic so accept it. [The course] makes you mentally more positive. You think diabetes all the time from the minute you wake up to the minute you go to sleep you think diabetes – you have to. But the way I am doing that is much more positively - it is not a pain, which I live with – it is something I am interested in.' (R13, male)

Theme 4. Lack of Motivation

Many negative responders felt they lacked motivation to manage their diabetes and make changes to treatment. There was often a feeling of inevitability that they would find it difficult to stay motivated and that improving motivation was not possible.

'It is just having a bit of willpower to stick to it – nothing you can do about that really.' (R3, male)

'I think it is in my hands to do something and I have got all the information and education I need but I just have to motivate myself to do it. Motivation is different for all people – but if you feel good about yourself – then you are more motivated to look after yourself and if you look after yourself then you feel better about yourself and so on.' (R9, female)

Positive responders were more likely to describe high levels of motivation to manage their diabetes and often recalled treatment goals.

'I can't just sit on my laurels and not have anything to aim at – having that aim keeps me motivated.' (R17, female)

Theme 5. Poor Family support

Participants were asked if their friends and family were supportive. All responders reported that they had sufficient support. However negative responders were more likely to report feeling unsupported or isolated from their family. However, this was often related to their reluctance to share anxieties with family and friends because they believed that they should be able to carry the burden of diabetes alone.

'My family are not supportive because I have always played it down, because I have never wanted to make a fuss – so I say I am alright which I am basically but sometimes it would be nice to have a little more attention but I have always felt that I have played it down.' (R9, female)

'*I just get on with it I suppose. I sometimes wish though that somebody else – I know it sounds awful – but that somebody in the family would get it – just to see exactly what we have to go through because people really don't know and they think diabetes is nothing. They don't know they have really got no idea what is involved with it. I do sometimes wish they knew what it was like.*' (R1, female)

6.4 Discussion

All participants reported benefits from attending the Bournemouth Type 1 Intensive Education Programme and the interaction with other people with diabetes was particularly useful. The similarity of psychological profiles at baseline and following the education programme in both groups would suggest that psychological morbidity alone is unlikely to account for the differences in glycaemic control following education. However interpretation is limited by the small sample size.

The interviews revealed clear differences in the perception of the two groups about their diabetes. The negative responders had difficulty accepting their disease on average 12 years after diagnosis. They struggled to sustain any motivation to manage their diabetes and often related this to long diabetes duration. They also reported a reluctance to elicit support from their family. In contrast, these issues were not a problem for the positive responders. They reported having accepted the diagnosis and were motivated to move forward with their diabetes management. It is proposed that the five themes (poor perception of diabetic control, accepting a chronic disease, negative thoughts, lack of motivation and lack of family support) act as barriers to change for the negative responders. As a result of these barriers, participants were not ready to change their health care behaviours at the time they attended the education programme and it is perhaps not surprising that they did not achieve an improvement in glycaemic control. It may be that acceptance of the diagnosis is the most important barrier and that the other barriers stem from an inability to come to terms with the diagnosis. Receiving the diagnosis of diabetes is a distressing time for many individuals, who often feel that they need more emotional support at diagnosis[159] and early denial, rather than current emotional well-being, is a better predictor of complications later in life.[160] Developing structured education programmes for patients at the time of diagnosis (as described in chapter 4) can help to reduce psychological distress at that time and may have an impact on glycaemic control in the long term.[161] They may also encourage acceptance of the diagnosis. The barriers identified in this study may contribute to low self-efficacy (the belief in one's capabilities to produce a certain level of performance required to manage prospective situations).[162] Higher self-efficacy is associated with better self-care behaviours, particularly for individuals with complex insulin requirements,[163] and is a significant predictor of later adherence to diabetes treatment.[164] In a general outpatient for patients with type 1 and 2 diabetes, belief in self-efficacy and active coping behaviour has been shown to be more relevant to treatment goals than other psychological variables.[165] Thus measuring self-efficacy prior to an educational intervention may also help in identifying those patients who are unlikely to fully benefit and improve glycaemic control following intensive education.

There is no uniform definition of a negative or positive responder. At the time this study was conducted, there were neither centrally defined standards nor outcome measures for education. The hospital diabetes team agreed a local standard that HbA1c should improve by at least 0.5% following participation in the BERTIE programme, in those with a baseline HbA1c > 8.0%. Glycaemic control is a fluctuating variable and it is recognised that control can both improve and deteriorate during the one year following the programme. This may have affected the definition of a positive or negative responder. However the HbA1c at one year was generally representative of subsequent levels. Only two negative responders improved their glycaemic control after the one-year follow-up and they attended the programme within the first six months of diagnosis.

The challenge for the future is to identify these barriers in individuals by assessing ‘readiness to change’, acceptance of diagnosis or self-efficacy prior to attending an education programme. ‘Readiness to change could be measured by using specific questions such as ‘I am intending to make to make changes in my diabetes management in the next six months’.[166] Patients could be allocated to a specific stage in the ‘Stage of Change’ model developed by Prochaska and Di Climente[167] and then offered the most appropriate intervention depending on their response. Alternatively a specific questionnaire such as the modified Stages of Change Readiness and Treatment Eagerness Scale (SOCRATES) can be used.[168] SOCRATES has been used in a general outpatient setting but no significant associations with lower levels of glycaemic control and higher levels of ‘readiness to change’ were seen. However, use of this questionnaire may be better suited prior to a specific intervention such as intensive education rather than an outpatient setting. Currently there are no quantitative methods to evaluate disease acceptance in diabetes. The Pictorial Representation of Illness and Self-Measure (PRISM)[169] has been used to assess the perceived burden of suffering due to illness in other chronic diseases although it is not known whether it would be useful in diabetes.

Self-efficacy can be measured using the Confidence in Diabetes Self-Care (CIDS) scale.[170]

The options for change are then either to address these barriers prior to intervention or to revise the education programme to incorporate motivational techniques and improve coping skills. More structured assessment prior to an educational intervention may identify those individuals who would benefit from a programme that focuses on developing motivation and improving readiness to change or self-efficacy, or specialised psychological intervention. These measurements should not be a way of precluding patients from attending an education programme should they wish to do so. Instead, the aim would be to improve ‘readiness to change’ so that patients can get the maximum benefit from education programmes.

7 Can a brief programme based on motivational interviewing improve glycaemic control and self-efficacy?

7.1 Introduction

Motivational Interviewing is a counselling approach that was developed in the addiction field by William Miller[171]. This approach is based on three fundamental approaches of collaboration, evocation and autonomy. ‘Collaboration’ represents the relationship between counsellor and patient which should be respectful of the patient’s perspectives. ‘Evocation’ refers to the assumption that individual have an intrinsic motivation to change which can be improved by focusing on their own perceptions, goals and values. Finally autonomy acknowledges the right of individuals for self-direction and aims to facilitate informed choice.[172] There are however four principles which guide motivational interviewing:

1. Expressing empathy. The empathic communication style should be used throughout motivational interviewing and combined with reflective listening to understand individuals’ feelings and perspective and not judge or criticise the individual. This results in an acceptance of the client’s view which may be ambivalent to change. However the client may then feel respected and less defensive and subsequently more likely to change behaviour.
2. Develop Discrepancy. Individuals are more likely to change behaviour if there is a degree of discrepancy between their current status and the goals they value for the future. Individuals who value their current status are less likely to change their behaviour but motivation for change is more likely to be found if they perceive a discrepancy from their desired status. The aim of the counsellor is to amplify and develop the discrepancy from individuals’ perspective until they feel motivated to change their behaviour beyond the status quo.
3. Roll with resistance. A person who is ambivalent about change is more likely to argue against behaviour change when recommended by a health care professional or counsellor. This is referred to as resistance and should be acknowledged and

accepted by the counsellor. The aim should be to give people an opportunity to develop new perspectives rather than trying to argue against the client.

4. Support Self-efficacy. Self-efficacy is individuals' confidence in their ability to carry out a specific task. The aim is to enhance an individuals' confidence in their ability to change behaviour.

The general approach is therefore client-centred and aims to enhance intrinsic motivation to change behaviour by exploring and resolving ambivalence and therefore may be a useful technique to achieve behaviour change in people with diabetes. To date three studies have looked at the use of motivational interviewing in adolescents with type 1 diabetes. In the first pilot study twenty-two adolescents participated in motivational interviewing sessions over a period of six months. The mean HbA1c decreased from 10.8% to 9.7% at the end of the study although complete data was only available for 11 participants. The study had a positive impact on the emotional aspects of diabetes and participants reported also that their diabetes had become easier to live with and a reduced fear of hypoglycaemia.[173] The second study used motivational interviewing in twenty-one young people with poorly controlled type 1 diabetes (HbA1c > 8.5%). A reduction of 1.5% in the HbA1c was seen after the intervention.[174] However these two studies were small and it is difficult to identify which component of the motivational interviewing related to clinically significant outcomes. A third later study again studied motivational interviewing in 66 adolescents. The results showed a significant improvement in glycaemic control of 0.6% at one year which was maintained at 2 years after the intervention.[175]

The aim of this pilot study was to determine whether motivational interviewing could improve glycaemic control in patients who did not improve their HbA1c following the intensive education programme and to establish in more detail the barriers to improving control.

7.2 Methods

7.2.1 Participants

Patients were identified from the intensive education database. Complete HbA1c data was available on 102 patients. Of these 33 showed no improvement, or a deterioration in HbA1c. Patients who had not improved their HbA1c by at least 0.5%, at one year following the education programme, and had a current HbA1c greater than 8% were invited to participate by letter.

7.2.2 Intervention

The programme consisted of 5 visits.

Visit 1:

Informed consent was collected at this visit. Participants were also asked to complete the psychosocial screening questionnaires. Baseline data on weight and HbA1c were collected at this time.

Baseline measurements of weight and HbA1c were also collected at this visit.

Visits 2-4:

These sessions were based on motivational interviewing techniques. The same researcher met with all participants. The researcher had training in motivational interviewing over six months consisting of workshops, role play and individual supervision. Four sessions on a weekly basis over four consecutive weeks were offered to all participants but each participant was responsible for deciding the location and number of sessions. The sessions lasted for 1 hour and took place at Bournemouth Diabetes and Endocrine Centre or at the participant’s place of work.

The content of the sessions, which was similar to other studies which have used motivational interviewing[173], used open questions and reflective listening to elicit the patients’ difficulties with diabetes and their ambivalence to behaviour change. The importance and confidence of participants with regard to changing specific behaviours was assessed. The participants were encouraged to set the agenda and the focus was on changing behaviours selected by the patient. Once the agenda was set, the pros and cons of the participants’ current behaviour was examined and alternative behaviours and problem solving were discussed. If the patient chose an alternative behaviour, realistic goals and a ‘change plan’ was negotiated.

The aim was to encourage patients to make significant changes in their self-care behaviour as a result of improved self-efficacy and to identify areas in which they required further support such as carbohydrate estimation or insulin adjustment. All patients were offered the opportunity to be referred to the dietitian, diabetes nurse specialist or psychologist.

7.2.3 Measures

The psychosocial questionnaires used in the study were:

- Hospital Anxiety and Depression Scale (HADS)[128] – The HADS was used as a measure of anxiety and depression. Scores between 11 and 21 are suggestive of significantly high levels. Participants were excluded if their scores were suggestive of high levels of depression but not anxiety. They were also given the opportunity if seeing the diabetes clinical psychologist.
- Problem Area in Diabetes (PAID)[71] – The PAID questionnaire was used as a measure of psychosocial adjustment to diabetes and in particular diabetes-related emotional distress.
- Confidence in Self-Care Scale (CIDS)[87] (appendix – This is a measure of the participants of the participants’ self-efficacy and provided information on how much the participants believe they can change their diabetes management
- Stages of Change Readiness and Treatment Eagerness Scale (SOCRATES)[97] (appendix 10) – The SOCRATES questionnaire will help to assess participants’ ‘readiness to change’ category according to the ‘Stage of Change Model’ developed by Prochaska and DiClemente.[96]

7.2.4 Outcome Measures

The outcome measures were HbA1c, self-efficacy scores on the CIDS questionnaire and PAID scores. These were collected one year after the intervention.

7.3 Results

25 individuals were invited to participate. 6 individuals agreed to participate. 1 participant did not feel able to continue with the study after 1 session due to other commitments. 5 participants completed the study but only 3 participants completed follow-up questionnaires.

7.3.1 Baseline Characteristics

Table 14 shows the baseline and 1 year characteristics and the HbA1c levels of the participants. Table 15 shows the mean psychological scores at baseline and 1 year. The stage of change on the SOCRATES questionnaire for each participant can be found in table 16. This table also includes the goals that were set by each participant and whether the participant felt that they had achieved that goal during the study.

Table 14 Baseline and 1 year characteristics

Age (mean ± SD)	42.9 ± 19
Duration diabetes (mean ± SD)	15.6 ± 9.9
Weight (mean ± SD)	69.2 ± 17.1
HbA1c baseline	9.5 ± 0.8
HbA1c 6 months	8.8 ± 0.6
HbA1c 1 year	9.0 ± 0.7
Smokers (%)	16
Gender (%)	50% male 50% female

Table 15 Baseline and 1 year psychological scores

		Baseline (mean ± SD)	1 year (mean ± SD)
PAID	Treatment	2.8 ± 2.0	2.3 ± 1.4
	Food	2.2 ± 1.9	1.3 ± 1.4
	Social	1.3 ± 2.0	1.0 ± 1.5
	Emotional	17 ± 11.6	15.7 ± 14.2
	Total	22.8 ±16	20.3 ± 16.8
HADS	Anxiety	8.3 ± 3.1	8.7 ± 2.7
	Depression	2.5 ± 1.4	2.0 ± 1.5
CIDS		86.5 ± 11.3	92.3 ±13.7

Table 16 Stage of change and goals set for each participant

	SOCRATES	Goals Set	Goals achieved	Referrals to other health care professional
Subject				
1	Action	Monitor one blood glucose level daily	Yes	Diabetes specialist nurse
		Give correction doses for hyperglycaemia	Yes	
2	Action	Blood Glucose monitoring one day a week	Yes	Diabetes specialist nurse for glucose sensor
		Food diary one day a week	No	
3	Maintenance	Review hypo treatment at work	Yes	None
		Healthier food shopping	No	
		Restart gym sessions	No	
4	Incomplete	Did not complete sessions	N/A	None
5	Contemplation	Start exercise programme	Yes	Dietitian
		Remember insulin injections when out	Yes	
6	Determination	Stop smoking	No	None
		Review diet and improve cholesterol	Yes	
		Trial of forearm meter	Yes	

7.3.2 Thematic Analysis

The transcripts from the sessions were analysed to explore the barriers which may have prevented patients from improving their diabetes control and the goals set by patients in the sessions

Theme 1: Unrealistic Expectations of Diabetes Management

Some participants found blood glucose monitoring difficult. They would often find high or low blood glucose levels which were unpredictable and with no obvious cause and described feeling demoralised. As a result they did not feel like continuing with monitoring. This could also relate to an HbA1c which discouraged further behaviour changes if it did not change at follow-up appointments.

'up until two years ago I'd spent two or three years trying so hard like doing blood testing up to 10 times a day and HbA1c every few months, carbohydrate counting, everything but it made no difference…it made no difference and I thought sod it, that hasn't made any difference so what is the point of spending all that time on it, it was frustrating.' R2, female

However participant 1 felt that high and low blood sugar levels were part of diabetes management. He felt they were unavoidable and therefore one should not be discouraged to see them. However he did feel that seeing an improving HbA1c could be encouraging.

'*I don't get so wound up, if I get a bad result I try to understand it a bit more, I accept it. You have got to expect you will have a bad result.'* R1, male

Theme 2: Incompatibility with life

Some participants felt that self-management of diabetes was not compatible with other aspects of life. They felt that certain jobs or hobbies precluded blood glucose monitoring, giving injections at the right time and treating hypoglycaemia properly and this resulted in poor diabetes control. They felt that as it was not possible to change their jobs, it was therefore not possible to carry out certain self-management skills.

'I fail to see how you can manage diabetes in my work environment' R6, male

Participant 1 felt that diabetes was a major factor in his life but that it was still possible to continue with all aspects of life such as his job and all hobbies with a little extra planning.

'You think it is interfering in your life and it is no doubt about it, but you have to get over that.' R1, male

Some individuals felt that their food choices were restricting and that it was necessary to eat food which was not enjoyable and 'boring' in order to manage their diabetes.

Theme 3: Difficulty with hypoglycaemia

All participants commented on the difficulty of hypoglycaemia despite improvements in treatment regimes and insulin delivery which can reduce the risk of hypoglycaemic episodes. For one participant the concern was that they lived alone and felt that hypoglycaemia should be avoided at all costs as it could result in significant morbidity and possible mortality. For other participants the concerns related to the symptoms which could be quite frightening. Another participant felt that hypoglycaemia could result in significant health and safety risks at work and felt reluctant to employ other people with diabetes because of the risk of hypoglycaemia.

'Just that out of control feeling, just the heat and the shakiness, it sounds crazy but you feel like you are dying, you do , you feel out of control, and you feel like if you are not going to sort this out, I mean you can die can't you, and you physically feel like that.' R2, female

Two of the participants felt that the appropriate treatment of hypoglycaemia was often difficult because of the disorientation and subsequently blood sugars could be much higher and difficult to treat.

Theme 4: Ongoing Support

Participants often felt that they increased the intensity of self-management skills at the time of appointments or at the time of education. One participant also found the intensive support provided at the time of starting an insulin pump helpful. They all felt that more regular support was needed to help maintain motivation. Refresher programmes were felt to be particularly helpful. One participant felt that knowledge about diabetes complications had been withheld and that he would have benefited from better knowledge about these issues. Medical appointments were not always thought of as the most appropriate support as consultations could be unhelpful and reinforce negative thoughts.

'The doctors say to me you might never be able to get it down, you might be one of these where it is too hard.' R 2, female

Theme 5: Lack of confidence

Four of the six participants felt that they did not possess the skills to improve their blood glucose levels and that changes in their management were unlikely to improve the situation. Thinking about changes to their diabetes management therefore appeared to be futile and overwhelming leaving the participants feeling isolated.

'It doesn't matter what I do, it doesn't make a blind bit of difference.' R4, female

'You never can get it right, you think you can but you can't.' R5, female

7.4 Discussion

This study did not show a significant change in the mean HbA1c, psychological scores or self-efficacy scores one year after the brief motivational interviewing programme. However it is difficult to comment on the data due to the very small sample size. The thematic analysis however did help to identify a number of barriers which may prevent people improving glycaemic control. Perhaps the most important themes are that of compatibility and a lack of confidence which could be encompassed by the lack of problem-solving abilities. Despite attending intensive education and insulin pump starts, which includes further education on carbohydrate counting and insulin dose adjustment, these patients struggled to find alternative solutions to self-management difficulties. If individuals fail to cope with a difficult situation, their confidence can decrease particularly when they need to deal with another problem and they can develop poor coping patterns.[176] Patients may need more support with developing problem-solving abilities during and after the intensive education programme and motivational interviewing may be useful for this. Participants were able to develop goals during the sessions and three participants reported positive changes in self-care behaviour during the sessions. However some studies which show improvements in self-care do not always show improvements in glycaemic control and other psychological barriers persisted. Two participants had high PAID scores. One individual did not complete the study. Both individuals were given the opportunity to see a psychologist but declined. Hypoglycaemia was identified as a significant problem for all patients. Insulin delivery and regimes have improved but the incidence of severe hypoglycaemia remains unchanged.[177] Hypoglycaemia can result in considerable psychological morbidity and it is important to recognise that it can be one of the most significant physiological and psychological barrier to improving glycaemic control.[178]

For some patients goals did not directly relate to glycaemic control and it may be that at that point losing weight or stopping smoking was more important to them than improving glycaemic control. This may be difficult for healthcare professionals specialising in diabetes to appreciate. However a better understanding of patients’ goals may reduce the resistance in the consultation and not distance patients with complex health care behaviours from the diabetes services.

The programme may be considered to be too brief to enhance behavioural change. However brief interventions have been shown to facilitate behaviour change[179] and may have similar results to longer programmes.[171] One of the other difficulties may be the experience of individuals carrying out the programme. Their experience was not dissimilar to those carrying out similar studies.[173] However further experience and supervision may have been helpful.

It is still difficult to establish the most suitable role for motivational interviewing in diabetes services. Motivational interviewing may allow better identification of psychosocial difficulties and poor self-efficacy skills. The CIDS questionnaire had been shown to be a reliable and valid diabetes self-efficacy questionnaire but the association with glycaemic control is weak and further studies are needed to show whether it is a useful screening questionnaire.[87] There are a variety of different self-efficacy questionnaires but they can be more concerned with psychosocial issues.[180] Comparison studies using different questionnaires may be helpful in determining the most useful questionnaire in the diabetes population.

The limitation of this study is the very small sample size. The response rate to the study invitation was poor. This may be related to the number of sessions which some individuals may have found time-consuming.

To conclude, this study did not show a change in glycaemic control or self-efficacy following a brief motivational interviewing programme. However the programme did help to elicit some of the barriers to improving control and patient goals. Further studies are needed to establish the use of MI in conjunction with intensive education and psychological services although it could be a useful communication tool in routine clinical care.

8 Discussion

The aim of this research was to use both qualitative and quantitative analysis to evaluate the services at Royal Bournemouth Hospital for people with type 1 diabetes from both a psychological and educational viewpoint and to explore how services could be improved. Initially focus groups were held to establish the views of patients, who had previously attended intensive education, on the services and in particular clinic assessments. Data collected at the focus groups demonstrated that routine clinic appointments were not always helpful for patients and failed to address all the management difficulties. Some participants felt that they would have benefited from the opportunity to see other health care professionals at the same time. However, it was striking how many patients referred to their experiences at the time of diagnosis of diabetes. The impact of the diagnosis for people with type 1 diabetes is often more severe than for those with type 2 diabetes[181] and information from the focus groups suggests that the care for individuals at this time needs to be more intensive. The ‘Living with Diabetes’ programme was set up for people with newly-diagnosed type 1 diabetes following the information from the focus groups. The aim of the programme was to improve knowledge about type 1 diabetes and basic carbohydrate counting but also to provide better support and improve psychosocial problems at a difficult time for patients. Patients who attended the programme showed significant improvements in HbA1c unlike patients who had conventional treatment at Royal Bournemouth Hospital. There were small improvements in psychological scores but these were not significant. However qualitative analysis suggested that patients who attended the programme felt in control of their diabetes and were more likely to describe problem-solving abilities with their diabetes management unlike patients who had conventional treatment at another hospital. They also benefited from support over the year which allowed them to explore their difficulties particularly with their peers; in contrast to patients who had conventional treatment who felt that they had good support at the time of diagnosis but that more support was needed at a later date when problems were more likely to develop. There are a number of paediatric programmes at diagnosis but only two programmes for adults.[139;182] However these programmes focus on educating patients in the first week after diagnosis. The ‘Living with Diabetes’ programme is the first to take place over a year and therefore may better suit patients' needs.

The analysis of the Bournemouth Type 1 Intensive Education programme established that this programme can help individuals with type 1 diabetes improve their HbA1c by 0.5% and that this improvement can be maintained over four years. This data is comparable to other programmes in the UK[183] and Europe.[146] Psychosocial screening questionnaires were completed in a group of patients before attending the programme and 1 year later. The results suggested that addressing concerns related to food is an important part of intensive education. More importantly improvements in glycaemic control following intensive education were associated with improvements in psychological distress, disordered eating and depression. However there is a significant group of patients who do not improve their control after completing the intensive education programme. A qualitative study of this group of patients showed that this group of patients were more likely to have a poorer understanding of their diabetes control, express negative thoughts, lack family and social support and struggled to accept their diabetes. The data also suggests that the level of psychosocial distress may deteriorate in this group of patients after completing intensive education. Patients may benefit more from intensive education by having these issues addressed earlier after diagnosis. Further work was carried out to determine whether a brief motivational interviewing programme could improve glycaemic control in patients who had not improved glycaemic control after intensive education. The HbA1c in this group of patients did not change significantly following the programme although some of the participants were able to develop goals during the programme which were achieved subsequently. However this group of patients lacked confidence in their ability to improve their diabetes control and felt that it was not possible to lead a 'normal' life and control their diabetes. This suggested that they had developed poor coping patterns and lacked problem-solving abilities. Further evaluation of other issues such as literacy and numeracy skills and psychosocial difficulties in this group of patients is needed to determine how these issues affect the response to structured education.

The main theme that is encompassed by this work is the difficulty for individuals at the time of diagnosis of type 1 diabetes. This was highlighted initially in the focus groups.

However the individuals who did not improve their diabetes control following intensive education and those who completed the motivational interviewing programme also described a number of problems such as difficulty accepting the diagnosis and lack of confidence with their diabetes management which may have stemmed from the time of diagnosis. This suggests this is one of the most important times for people with type 1 diabetes and as such requires a higher level of care than previously provided.

Appropriate care is needed not only immediately after the diagnosis but throughout the year after diagnosis, to help people develop good coping skills and problem-solving abilities and to foster better acceptance. Peer support is also needed alongside that of healthcare professionals to facilitate those skills. Insulin dose adjustment and carbohydrate counting is an essential component of self-management. Patients with previous experience of carbohydrate counting prior to completing the intensive education programme were found to have significantly better glycaemic control. This suggests the importance of introducing these skills earlier after diagnosis so that the intensive education programme can help to consolidate knowledge and self-management rather than introduce these skills for the first time.

The experience of patients interviewed suggests that the Bournemouth “Living with Diabetes” programme provides the necessary care following diagnosis and throughout the following year, whilst providing peer support from an early stage. This may improve psychological distress and self-management skills whilst promoting better acceptance of diabetes. Further analysis of the LWD programme is needed to determine whether the programme leads to long term benefits in terms of improved glycaemic control and reduced psychological distress. If confirmed, this may be a model which other diabetes services may wish to adopt.

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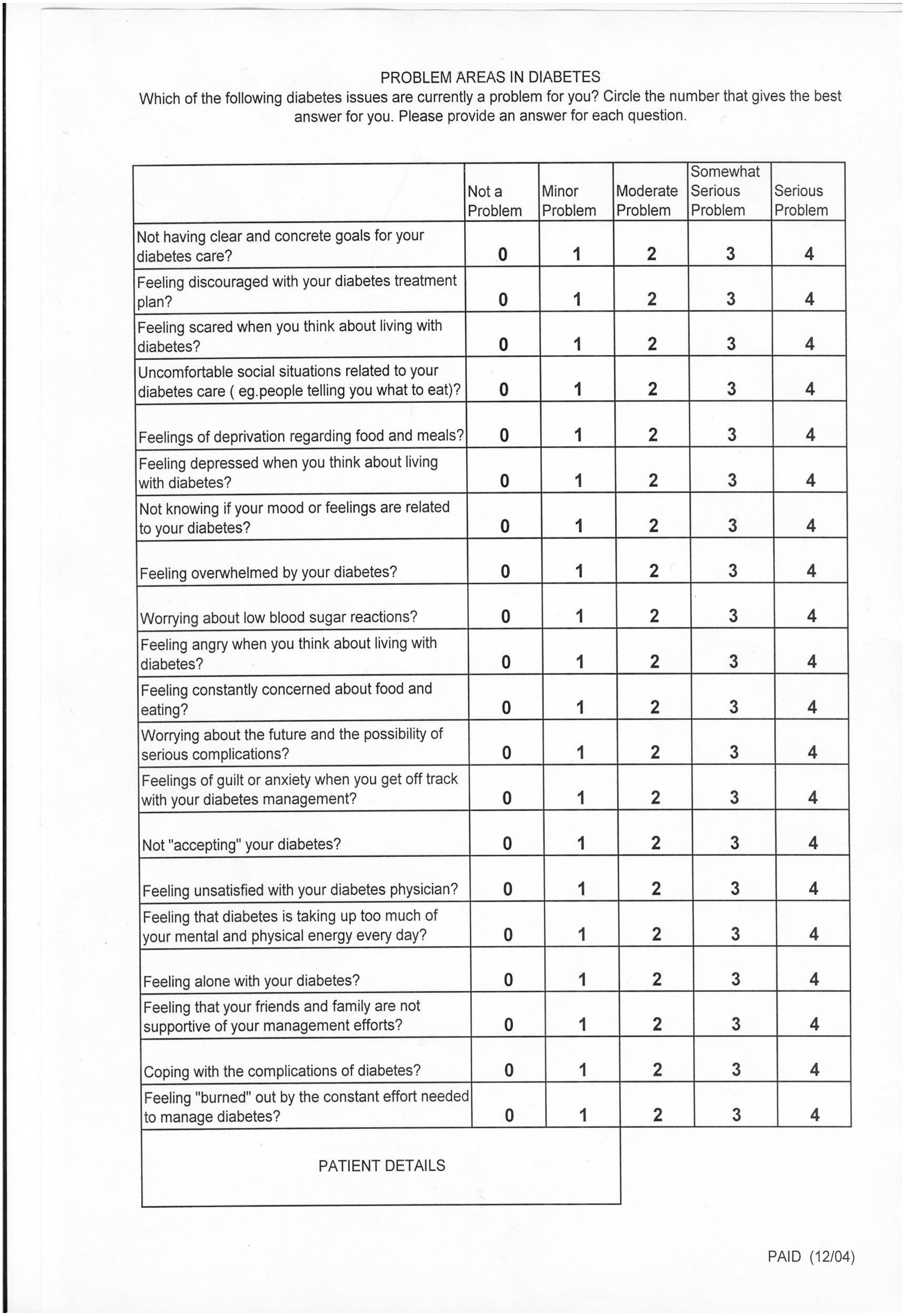
Ref Type: Abstract

Appendix 1 : HADS Questionnaire

Appendix 2 : PAID questionnaire



PROBLEM AREAS IN DIABETES

Which of the following diabetes issues are currently a problem for you? Circle the number that gives the best answer for you. Please provide an answer for each question.

	Not a Problem	Minor Problem	Moderate Problem	Somewhat Serious Problem	Serious Problem
Not having clear and concrete goals for your diabetes care?	0	1	2	3	4
Feeling discouraged with your diabetes treatment plan?	0	1	2	3	4
Feeling scared when you think about living with diabetes?	0	1	2	3	4
Uncomfortable social situations related to your diabetes care (eg.people telling you what to eat)?	0	1	2	3	4
Feelings of deprivation regarding food and meals?	0	1	2	3	4
Feeling depressed when you think about living with diabetes?	0	1	2	3	4
Not knowing if your mood or feelings are related to your diabetes?	0	1	2	3	4
Feeling overwhelmed by your diabetes?	0	1	2	3	4
Worrying about low blood sugar reactions?	0	1	2	3	4
Feeling angry when you think about living with diabetes?	0	1	2	3	4
Feeling constantly concerned about food and eating?	0	1	2	3	4
Worrying about the future and the possibility of serious complications?	0	1	2	3	4
Feelings of guilt or anxiety when you get off track with your diabetes management?	0	1	2	3	4
Not "accepting" your diabetes?	0	1	2	3	4
Feeling unsatisfied with your diabetes physician?	0	1	2	3	4
Feeling that diabetes is taking up too much of your mental and physical energy every day?	0	1	2	3	4
Feeling alone with your diabetes?	0	1	2	3	4
Feeling that your friends and family are not supportive of your management efforts?	0	1	2	3	4
Coping with the complications of diabetes?	0	1	2	3	4
Feeling "burned" out by the constant effort needed to manage diabetes?	0	1	2	3	4

PATIENT DETAILS

PAID (12/04)

Appendix 3: Questionnaire for focus groups.

This questionnaire will be asking you questions about your recent clinic visits to the diabetes centre. All information is confidential and in any reports or publications, comments will be anonymised and you will not be identified in any way.

1. How long have you had diabetes? ………..years

2. How old are you? …………years

3. When was your last visit to Bournemouth Diabetes and Endocrine? …………….

4. Please circle who you saw (you can circle more than one)

Doctor Dietitian Nurse Psychologist Dietitian

5. Would it have been useful to see any of the below at the same visit?

Doctor Dietitian Nurse Psychologist Dietitian

6. Was there a specific reason for your appointment? (please circle)

YES NO

Comments:

7. If you answered yes to the above, was the reason attending met?

YES NO

8. Were there any specific issues that you wanted to talk about?

YES NO

Comments:

9. Were you able to discuss these issues?

YES NO

Comments:

10. If yes, were you given enough time to talk about them?

YES NO

Comments:

11. If you answered ‘NO’ to question 8, what were the reasons?

12. Were you asked any questions about you social life e.g. family, work, life events?

YES NO

If yes please specify:

13. Did you feel that the person you saw was interested in: (you may circle more than one)

    a. Medical results

    b. Diabetes management

    c. You as a person

    d. How you are coping with your diabetes

14. If you ticked more than one category in the above question, what was the main interest?

15. What do you expect from a clinic visit to the hospital?

16. How can clinic visits be improved?

17. Any other comments?

Thank you for completing the questionnaire.

Appendix 4: Questionnaire for patients with newly-diagnosed diabetes.

1. How did you feel when you were diagnosed with diabetes?

2. How did you feel about diabetes now?

3. What is your diabetes control like now?

4. How do you feel about the support you have had since you were diagnosed with diabetes?

5. How do you feel about the support you have had since you were diagnosed with diabetes?

6. What aspect of your diabetes management do you find most difficult?

7. In what way did you find the programme helpful?

8. What did you find unhelpful?

9. What is the most important thing you have learnt in the last year?

10. How confident are you in making changes to your diabetes management?

11. What would stop you making changes to your diabetes management?

12. What worries you most about your diabetes?

13. How does the way in which you feel affect how you look after yourself?

14. Is there anything that stops you making changes to your diabetes management?

15. What aspects of your life are important to you?

16. How comfortable are you talking to other people about your diabetes?

17. Is there anything else you would like to say?

Appendix 5. Timetable for Bournemouth Intensive Education Programme

Week 1

Time	Topic	Health Professional	Workbook pages
9.15 am	Introduction: • Get to know each other • Introduce education programme • Define own goals and expectations • Introduce workbook • Introducing psychological support	DNS Dietitian Psychologist	P 3-5
10.30	What is diabetes? • Normal ranges of blood glucose levels • How does insulin lower blood glucose • Need for constant supply of insulin • Need for insulin to cover food intake	DNS	P 6-7 & diagram p 46
11.00	Break		
11.15	Introduction to Carbohydrate Counting	Dietitian	P 11-12, 14, 16-18
12.45	Monitoring blood glucose targets	All	P 17
1.00	Buffet meal together and estimation of carbohydrates		
2.00	Action of insulin: • Action of insulin regimen • Variations of insulin requirements Monitoring: HbA1c – What does this mean? • Storage of insulin • Injection sites and technique	DNS DNS	P 8-9 P 10, 18 P 57
	Homework • Familiarise yourself with carbohydrate values of food • Discuss strategies for insulin doses for the coming week • Consider personal goals • Complete food and insulin diaries Plan for coming week		

Week 2

Time	Topic	Health Professional	Workbook pages
9.15	Feedback from week's experiences Discussion of insulin dose adjustment Review individual goals	All	
10.30	Break		
10.45	More on carbohydrate Counting: • Reading labels • Difficult to measure foods	Dietitian	P 12-15
1.00	Buffet meal together and estimation of carbohydrates		
1.30	Hypoglycaemia: • Define Hypoglycaemia • Symptoms of hypoglycaemia • Common causes of hypos • Hypoglycaemia – unawareness • Treatment including Glucagon	DNS	P 21-22 P 23-24
2.30	Exercise- overview • Discuss own physical exercise • Replenishment of energy stores • Management of insulin and food during exercise • Reasons when exercise should not be done e.g. ketonuria	All	P 35-36 P 52
	Homework: • Think about whether correct insulin was given at a previous meal time • Is your dose of background insulin correct? • Complete food and insulin diaries • Complete exercise diary • Plan for coming week	All	

Week 3

Time	Topic	Health Professional	Workbook pages
9.15am	Feedback from week's experiences Discussion of insulin dose adjustment	All	
10.30	Break		
10.45	Hyperglycaemia and Ketoacidosis: • Symptoms/causes of high blood sugars • Formation of ketoacidosis • Signs/treatment of ketoacidosis • Examples of when to increase insulin	DNS	P 25-29
11.45	Nutrition • Eating out • Takeaways	Dietitian	
1pm	Meal together		
1.30	Nutrition – Alcohol	Dietitian	P 33-35
2.30	Exercise • Reasons for potential hypoglycaemia • Review of own exercise	All	P 36-37, 52
	Homework • Think about how well your meal ratios are working • Is your dose of background insulin) correct? • Is your dose correction dose correct? • Complete food and insulin diaries Plan for coming week		

Week 4

Time	Topic	Health Professional	Workbook pages
9.15	Feedback from week's experiences Discussion of insulin dose adjustment Review personal goals	All	P 19
10.30	Break		
10.00	Diabetes and long term health Understanding clinic visits & blood tests	Doctor	P 39-43
11.00	Psychological issues & diabetes	Psychologist	P 38
11.45	Nutrition Review Carbohydrate Counting/ Glycaemic Index/Healthy Eating	Dietitian	P 30-32
12.15	Travelling Pregnancy	DNS	
12.45	Reflection and Evaluation Set date for review	All	
1.15	Pub meal together		

Appendix 6: Introduction to Carbohydrate Counting/Understanding CP Values

Time allocation: 60 minutes

Learning objectives

1. To describe how and why dietary advice for type 1 diabetes had changed.
2. To understand the current philosophy of freedom in dietary choices.
3. To be able to describe which foods contain carbohydrate (therefore require insulin) and compare with sources of fat & protein.
4. To be able to explain that a CP provides 10g carbohydrate and that the CP values of food is provided in reference tables.
5. To have practised adding up the CP values in a typical meal.
6. To understand that meal insulin doses are determined using an insulin:CP ratio which can range from ½ to 3units :CP.
7. To know to start using 1unit per CP (or other as determined through discussion with DNS/dietitian) or continue with currently used ratio.
8. To know to examine effectiveness of insulin:CP ratio by recording data on diaries and reviewing blood glucose values.

Specific aspects of theory	Educator activity	Participant activity	Resources
Verbal persuasion/elicitation of knowledge Emotion management; verbal persuasion/elicitation of knowledge; role modelling Mastery experience	Educator will cover each section by: 1. eliciting participants current level of knowledge 2. asking questions and respond to answers to increase understanding 3. using participants experiences to learn from each other 4. Asking if participants have any further queries before moving on to next section	Each participant will be encouraged to: 1. Recall knowledge and reflect on experiences and consider current dietary guidelines 2. practise determining sources of CHO using food models and compare with protein/fat containing foods. 3. begin to work out CP values of foods using tables and example meals. 4. Respond to questions using own knowledge. 5. Use responses of self and of fellow participants to increase understanding 6. Reflect on personal experiences and those of peers when learning about use of insulin:CP ratios 7. Work out meal insulin doses based on 1:CP ratio (or other) 8. Be able to express any anxieties about using ratios or the doses calculated from ratios 7. Start recording data in monitoring diaries	Flipchart and pens Type 1 handbook Food models CP tables Monitoring diaries

Learning outcomes/ opportunities	**Educator activity**	**Notes**
Dietary overview		
To be able to describe how and why dietary advice for type 1 diabetes had changed.	The educator will write down participant experiences and use this information to explain history of dietary advice and emphasise the importance of relating CHO intake with insulin.	Educator will encourage all to participate and patients' own words will be written down on flipchart
To understand the current philosophy of freedom in dietary choices.	Educator will outline how current approach to CHO counting may be different-relating to modern insulin action (refer to DNS session on insulin action). Explain freedom to enjoy 'normal' food choices but emphasise consideration of healthy balanced diet in line with non-diabetic recommendations	Check insulins used by participants. Consider past dietary advice and respect experiences and reservations of participants.
Carbohydrate Values		
To be able to describe which foods contain carbohydrate (therefore require insulin) and compare with sources of fat & protein.	Activity-group to use food models to separate CHO and non-CHO foods. Support & question group decisions. Summarise result of group work by identifying nutrients Document on flip chart – purpose & sources, which effect BGLs (Fat, Protein,Alcohol) Carbohydrate – look at specific sources Compare CHO choices with healthy eating choices.	Use knowledge/understanding and experiences of group to illustrate points. What has worked in the past? Is there any confusion with advice given re healthy eating?
To be able to explain that a CP provides 10g carbohydrate and that the CP values of food is provided in reference tables.	Educator will explain to group that CHO content varies in different sources by using flip chart examples. Show how to estimate amount of CHO in food by using CPs – 1 CP =10g carbohydrate.	Educator will use participants knowledge and experiences to help group reflect and gain understanding

	Introduce CP tables	
To have practised adding up the CP values in a typical meal.	Educator will ask participants for example meals and go through process of calculating CP values.	Educator will check understanding of all participants
Insulin:CHO ratios		
To understand that meal insulin doses are determined using an insulin:CP ratio which can range from ½ to 3units :CP.	Educator will show that insulin doses are determined according to CPs by using ratio. Ratio is individually determined but ranges from ½ -3 units per CP. Most usual to start with 1 unit per CP. Educator will consider individuals who already use other ratios and question its effectiveness.	Those who already use ratios can feedback on their experiences to peers. Use flip chart.
To know to start using 1unit per CP (or other as determined through discussion with NDS/dietitian) or continue with currently used ratio.	Check ratios currently being used by participants. For others ask to start using 1:CP ratio in agreement with individual. Review current doses and consider other ratios if doses usually less than 1:CP or if very large doses currently used and patient identified as having degree of insulin resistance.	Participants will not be asked to use ratio that would give greater insulin dose than present dose. They should be able to express any anxieties about these insulin doses
To know to examine effectiveness of insulin:CP ratio by recording data and reviewing blood glucose values.	Educator records monitoring process on flip chart, emphasizing need to record BG responses to meals in order to evaluate effectiveness of meal ratios. Instruct participants to follow this process over lunch meal and for rest of following week.	Participants are reminded to wash hands prior to performing blood test. Use only pre-meal BG values for first week.
To recall main points from lesson	Recap main points of lesson using flipchart and work book	

Appendix 7: Psychological Issues and Diabetes

Process**:** The educator will ask specific questions to invite the participants to reflect on the interaction between their thoughts, feelings and behaviour. Information will be written on flip chart under headings and used to illustrate helpful and unhelpful interactions, vicious circles and barriers to self management. The educator will facilitate interactive discussion.
The participants will be encouraged to reflect and share experiences.

Time allocation 20-30 minutes.

Learning objectives:

1. to be able to recognise factors that influence acceptance and adjustment to living with diabetes
2. to recognise the influence of mood on individual self care behaviours
3. to understand how beliefs about diabetes and unhelpful thoughts have been challenged during the course and identify subsequent changes in self management
4. to know how to access emotional and psychological support

Specific aspects of theory	Educator activity	Participant activity	Resources
Emotion management Emotion management Verbal persuasion Elicitation of knowledge	Educator will cover each section by 1. asking participants what it means to live with diabetes (reflecting on goals from session 1) 2. eliciting participants thoughts, feelings and behaviours and interpreting the interactions 3. consider alternative interactions 4. asking questions and respond to answers to increase understanding 5. using participants experiences to learn from each other 6. asking participants about where they might access emotional / psychological support and providing relevant information 7. asking if participants have any further queries before moving on to next section	Each participant will be encouraged to: 1. share their own thoughts and feelings 2. consider whether the way they feel influences what they do 3. Respond to questions using own knowledge. 4. use responses of self and of fellow participants to increase understanding 5. contribute individual specific issues 6. reflect on changes that they may already have made	Flipchart and pens

Learning outcomes/ opportunities	**Educator activity**	**Notes**
Factors that influence acceptance and adjustment		
To be able to list factors that influence acceptance and adjustment to living with diabetes	The educator will ask participants what it means to them individually to live with diabetes	Use actual experiences of group
Mood		
To be able to recognise the way in which mood interacts with thinking and behaviour to influence self management	Educator will ask participants to give examples of thoughts, feelings and behaviours related to diabetes and record the sequences on a flip chart	Educator will offer examples if necessary to illustrate the process.
Recognise what influences mood	Educator will ask participants if there are times when other things seem more important than managing diabetes optimally	Educator will use participants experiences to help group understand the interaction
Unhelpful thoughts and beliefs		
To understand how beliefs about diabetes and unhelpful thoughts have been challenged during the course and identify subsequent changes in self management	Educator will ask participants to offer examples of thoughts and feelings that have changed during the course as a result of information and sharing the experience of others	Educator will use participants experiences to help group understand the interaction
Accessing emotional and psychological support		
To know where to go to seek support	Educator will describe the continuum of concerns in line with the pyramid model of psychological care. Elicit participants knowledge of local support systems. Educator will provide information about how to access professional support.	
Review	Any further comments or questions	

Appendix 8: Questionnaire for non-responders and responders to intensive education.

1. How old are you?
2. Male or female?
3. What age were you diagnosed with diabetes?
4. What job do you do?
5. Are you a smoker?
6. How much alcohol do you drink?
7. What is you weight?
8. What was your control like before attending the education programme?
9. What did you find helpful about the programme?
10. What was there in the programme that you had not known before?
11. Was there anything in the programme that you found unhelpful?
12. How has your lifestyle changed since attending the education programme?
13. How has your diabetes management changed?
14. What do you think your control is like now?

15. What aspect of your diabetes management do you find most difficult to cope with?

16. What problems have you had with hypoglycaemia?

17. What problems have you had with injections?

18. How confident are you managing your diabetes?

19. What worries you most about your diabetes?

20. What would help you to deal with this/these problem/s?

21. Do you think that there is anything that could be included in the programme to help you manage your diabetes better?

22. What support do you have?

23. Is there anything else that you would like to say?

Thank you for your time.

Appendix 9: CIDS questionnaire

ID________

Date__________

CONFIDENCE IN DIABETES SELF-CARE

Instructions:
After each of the following statements, circle the number that best indicates how much YOU BELIEVE you can or cannot do what is asked. Please note that the questions ask not what you should do but what you BELIEVE you can do.

I believe I can:	**No, I am sure I cannot**	**No I don't think I can**	**I am not sure**	**Yes I think I can**	**Yes I'm sure I can**
1. ...plan my meals and snacks according to dietary guidelines.	1	2	3	4	5
2. ...check my blood glucose at least 2 times a day.	1	2	3	4	5
3. ... perform the prescribed number of daily insulin injections.	1	2	3	4	5
4. ...adjust my insulin for exercise, traveling, or celebrations.	1	2	3	4	5
5. ...adjust my insulin when I am sick.	1	2	3	4	5
6. ...detect *high* levels of blood sugar in time to correct.	1	2	3	4	5
7. ...detect *low* levels of blood sugar in time to correct.	1	2	3	4	5
8. ...treat a *high* blood sugar correctly.	1	2	3	4	5
9. ...treat a *low* blood sugar correctly.	1	2	3	4	5
10. ...keep daily records of my blood sugars.	1	2	3	4	5
11. ...decide when it=s necessary to contact my doctor or diabetes educator.	1	2	3	4	5
12. ...ask my doctor questions about my treatment plan.	1	2	3	4	5
13. ...keep my blood sugars in the normal range when under stress.	1	2	3	4	5
14. ...check my feet for sores or blisters daily every day.	1	2	3	4	5
15. ...ask my friends or relatives for help with my diabetes	1	2	3	4	5
16. ...inform colleagues/others of my diabetes, if needed.	1	2	3	4	5

17. ...keep my medical appointments.	1	2	3	4	5
18. ...exercise 2 to 3 times weekly.	1	2	3	4	5
19. ...figure out what foods to eat when I am dining out.	1	2	3	4	5
20. ...read and hear about diabetes complications without getting discouraged.	1	2	3	4	5
21. ...manage my diabetes well overall.	1	2	3	4	5

Appendix 10: SOCRATES questionnaire

Please **circle one number for each question,** to show how much you agree or disagree with it. There are no right or wrong answers, so don't spend too long with each one.

NAME: DATE:

		strongly disagree	**disagree**	**unsure**	**agree**	**strongly agree**
1	**I really want to make changes in how I look after my diabetes.**	**1**	**2**	**3**	**4**	**5**
2	**There are times when I wonder whether I should look after my diabetes better.**	**1**	**2**	**3**	**4**	**5**
3	**I definitely have some problems related to looking after my diabetes.**	**1**	**2**	**3**	**4**	**5**
4	**I have already started making some improvements in my diabetes.**	**1**	**2**	**3**	**4**	**5**
5	**I was not looking after my diabetes properly at one time but I have managed to change that.**	**1**	**2**	**3**	**4**	**5**
6	**The only reason I come to clinics is that somebody makes me.**	**1**	**2**	**3**	**4**	**5**
7	**Sometimes I wonder if I'm not looking after my diabetes properly.**	**1**	**2**	**3**	**4**	**5**
8	**I really want to do something about how I look after my diabetes.**	**1**	**2**	**3**	**4**	**5**

9	I’m not just thinking about improving my diabetic control, I’m already doing something about it.	1	2	3	4	5
10	I have already improved how I look after my diabetes, and I am trying to keep from slipping back to my old pattern.	1	2	3	4	5
11	I have serious problems looking after my diabetes.	1	2	3	4	5
		strongly disagree	disagree	unsure	agree	strongly agree
12	Sometimes I wonder if my poor diabetic control is hurting other people	1	2	3	4	5
13	Sometimes I don’t look after my diabetes.	1	2	3	4	5
14	I am actively doing things now to improve how I look after my diabetes.	1	2	3	4	5
15	I used to have problems with looking after my diabetes but not any more	1	2	3	4	5
16	I think I need to be coming to the clinic for help with looking after my diabetes.	1	2	3	4	5
17	I wonder if not looking after my diabetes is bad for me.	1	2	3	4	5
18	If I don’t improve my diabetic control soon, my problems are going to get worse.	1	2	3	4	5
19	I have already been trying to improve my diabetic control, and I am here to get more help with it.	1	2	3	4	5
20	Now that I have improved how I look after my diabetes, it is important to hold onto the changes I’ve made.	1	2	3	4	5
21	I know that I have a problem with how I look after my diabetes.	1	2	3	4	5

22	I am uncertain whether I look after my diabetes properly	1	2	3	4	5
23	It is definitely time for me to do something about the problems I have been having in looking after my diabetes.	1	2	3	4	5
24	I have started to carry out a plan to look after my diabetes control.	1	2	3	4	5
25	I want help to keep from going back to the problems that I had before with looking after my diabetes.	1	2	3	4	5
		strongly disagree	disagree	unsure	agree	strongly agree
26	I am fairly normal in how I look after my diabetes.	1	2	3	4	5
27	Sometimes I wonder if I am not in control of how I look after my diabetes.	1	2	3	4	5
28	I don't look after my diabetes that well.	1	2	3	4	5
29	I am working hard to improve my diabetic control.	1	2	3	4	5
30	I am worried that my previous problems with looking after my diabetes might come back.	1	2	3	4	5
31	I've had more trouble with looking after my diabetes than most people do.	1	2	3	4	5
32	I don't think I have any particular 'problem' with looking after my diabetes.	1	2	3	4	5
33	I have a problem looking after my diabetes.	1	2	3	4	5
34	I know that my poor diabetic control has caused problems, and I am trying to do something about it.	1	2	3	4	5
35	I have made some improvements in looking after my diabetes, and I want to keep it that way.	1	2	3	4	5

36	**My problems are at least partly due to diabetic control.**	**1**	**2**	**3**	**4**	**5**
37	**I don’t know whether or not I should change how I look after my diabetes.**	**1**	**2**	**3**	**4**	**5**
38	**How I look after my diabetes is causing a lot of harm.**	**1**	**2**	**3**	**4**	**5**
39	**I have a serious problem with looking after my diabetes, and I have already started to overcome it.**	**1**	**2**	**3**	**4**	**5**
40	**I look after my diabetes well and I want it to stay that way.**	**1**	**2**	**3**	**4**	**5**