Factors Affecting Uptake of an Education and Physical Activity Programme for Newly Diagnosed Type 2 Diabetes

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Abstract

The majority of individuals diagnosed with Type 2 diabetes are overweight, do not engage in recommended levels of physical activity or follow guidelines for dietary intake. However, intensive lifestyle intervention of weight reduction and moderate physical activity has been shown to help regulate and even prevent Type 2 diabetes. This study sought to explore factors affecting uptake of an Education and Physical Activity Programme for those diagnosed with Type 2 diabetes. Focus group discussions were conducted with 11 individuals who had completed the course in the previous six months. Semi-structured interviews were conducted with 10 individuals who had declined the invitation to attend the course after being diagnosed with Type 2 diabetes. All data were analysed using a thematic framework approach and a number of key similarities and differences between the groups were identified. Participants in the programme appeared to have received clearer messages about the severity of unmanaged diabetes, whereas non-attenders felt their existing co-morbidities posed greater risks to their health. There were major concerns amongst both groups about undertaking exercise, and strategies for diabetes management focused heavily on dietary modification. The findings of this study suggest that fears and lack of understanding about both diabetes and exercise can act as significant barriers to accessing an education and physical activity programme, and also to maintaining higher activity levels following completion of such a programme. These findings are supported by the literature and highlight the need for more tailored programmes of lifestyle intervention for those diagnosed with Type 2 diabetes.

Keywords: Type 2 diabetes, education, physical activity, patient experiences, self-management, lifestyle.

Key Points

- People with Type 2 diabetes tend to be overweight and often do not follow guidelines for physical activity or dietary intake.
- Intensive lifestyle intervention can improve glucose tolerance and even prevent the onset of Type 2 diabetes amongst at-risk groups.
- Barriers to participation in a programme of education and physical activity include poor understanding of the severity of uncontrolled diabetes, the competing priorities of different illnesses, and fears about undertaking exercise.
- Treatment on diagnosis and communication with key health professionals are important factors in an individual's decision to attend such a programme or modify their lifestyles.
- Patients perceive that there is some stigma attached to having Type 2 diabetes and that meeting others in a similar situation can either add to or help remove this stigma.
- Interventions should take individual concerns and preferences into account, as well as attempting to overcome the various age- and health-related barriers to attendance.
- Further work is needed to explore the most appropriate methods for increasing and sustaining physical activity levels amongst older adults and those with Type 2 diabetes.

Introduction

People diagnosed with Type 2 diabetes need education to understand and accept their condition and manage it successfully. [1] The importance of structured diabetes education is set out in the Diabetes National Service Framework (NSF) and reinforced by guidance from the National Institute of Clinical Excellence on the use of patient education models for diabetes. [2,3] Although structured education programmes can impart information on the importance of exercise and lifestyle intervention for glycaemic control, the implementation of these changes is left to the individual. Dietary intake and exercise levels remain worryingly poor among people with Type 2 diabetes, and the majority do not engage in recommended levels of physical activity, tend to be overweight and do not follow guidelines for diet. [4]

A number of studies have demonstrated improvements in blood glucose (HbA1c) levels and BMI using educational approaches. [5-12] However, educational programmes alone have had little long-term effect on increasing physical activity levels amongst people with Type 2 diabetes. [10, 12, 13] This is in contrast to evidence which shows that regular moderate intensity activity can produce small but significant improvements in blood glucose control. [14] In those with impaired glucose tolerance, intensive lifestyle intervention of weight reduction and moderate activity can actually prevent the onset of Type 2 diabetes. [15] Exercise programmes can be of benefit, helping to reduce HbA1c levels and increase physical activity amongst participants. [16-19] Both aerobic and resistance exercise programmes produce similar benefits, although higher levels of intensity of physical activity result in greater improvements. [14]

In Newcastle-upon-Tyne in the northeast of England, all patients newly diagnosed with Type 2 diabetes are referred by their general practitioner (GP) to specialist dietetic services, where they are seen within four weeks of receipt of the referral. At the first appointment with the dietitian, they are invited to participate in an Education and Physical Activity Programme run by Diabetes Specialist Nurses in one of six leisure centres strategically located across Newcastle. Each session of the initial eight-week course is two hours long and includes a 45-minute talk on an aspect of diabetes management, followed by one hour of supervised exercise. The format of the sessions is informal group work, with the emphasis on everyone taking part. Around twenty courses run each year and approximately 50 per cent of those referred to the programme take up the offer to attend.

We report here the results of a study that represents the qualitative strand of a wider service evaluation of the Newcastle Education and Physical Activity Programme for Newly Diagnosed Type 2 Diabetes. The principal aims of the study were to: (1) explore experiences, views and perceptions of the programme amongst service users, and (2) identify strategies to remove potential barriers to attendance and increase access to the programme. The study involved focus groups with people who had participated in the programme and semi-structured interviews with those who had declined the invitation to attend after being diagnosed with Type 2 diabetes. See Table 1 for characteristics of the study participants. The research was granted a favourable opinion by Newcastle and North Tyneside Local Research Ethics Committee.

Methods

Recruitment of programme participants took place via the Diabetes Nurse Specialists at a follow-up session six months after completion of the eight-week course. Two focus groups were conducted, one in the west end (n= 8) and the other in the east end of Newcastle (n= 3), at centres that had been used for the programme. One member of the research team facilitated the discussions (SV), whilst another observed and made notes on participants' interactions (BH). The focus group method was felt to be most appropriate in this context as it explicitly uses group interaction to produce data and insights, and is particularly useful when seeking to explore the degree of consensus on a given topic. [20]

Individual interviews were felt to be more suitable for gathering the views of non-attenders, as the group format was potentially a factor in their decision not to attend the programme. A purposive sampling strategy was used to select 12 individuals for interview, taking into account age, gender and socioeconomic status. The Diabetes Nurse Specialists provided details of these non-attenders, who were then contacted by letter from their GP on practice-headed notepaper. This method has previously been shown to increase response rates amongst hard-to-reach groups. [21] The interviews lasted for roughly one hour and took place at a mutually convenient venue, either the client's home (n= 11) or within Newcastle University (n= 1).

The topic guides were created with input from the Diabetes Specialist Nurses, after reviewing the research literature and initial evaluation findings. The principal content areas of the focus group guide included access to the service, format and content of

the sessions, and perceived impact of the programme. Participants were also specifically asked about exercise after the quantitative strand of the evaluation revealed consistently poor levels of self-reported physical activity. The interview guide for non-attenders included probes to inquire about their medical background, quality of life, knowledge of diabetes and reasons for non-attendance on the programme. This guide was piloted prior to use as part of an MSc project by one of the researchers (SB).

Data gathered during the interviews was audiotaped and transcribed, with the exception of two cases. One patient had subsequently attended the programme and another could not be prompted to discuss the topic at hand, despite the best efforts of the researcher. The first focus group was audiotaped and transcribed verbatim, with a researcher then listening to the tape to verify the transcription. Despite providing their written consent, a member of the second group expressed some discomfort at the suggestion of having the session audiotaped and instead the observer attempted to take detailed notes of the discussion. These notes were verified by the facilitator immediately following close of the session.

The notes and transcripts arising from the discussions were analysed by members of the research team to identify the main concepts within the data and to draw out common themes and differences. Trustworthiness of data interpretation was addressed by having three members of the research team independently analyse the transcripts, i.e. triangulation of analysis. [22] A thematic content/framework approach was used, whereby each phrase is examined, coded according to the themes within it and considered in terms of its context in the discussion. [23, 24] Categories identified in this

way were grouped to form themes that reflect the main factors affecting uptake of the programme from participants' and non-attenders' perspectives. The themes presented here are those considered to be most important in informing future service design.

Results

The focus groups and interviews generated a rich description of the range of views and experiences of the Education and Physical Activity Programme. The synthesis of data from these two avenues of investigation enabled the identification of four key themes. These are summarised in Table 2 and described in more detail below, illustrated with the use of direct quotations from study participants.

Barriers to accessing the service

Diagnosis

The significance placed on an individual's diabetes and the perceived need to attend the programme were often linked to their treatment on diagnosis. Non-attenders reported being told that their condition was "borderline" and that they were managing well on their own, making it difficult for them to understand the potential value of the programme.

> "I've never seen a doctor about diabetes, it's always just been the nurses… there's nothing that's aroused any sense of importance, to me it's always been a minor, minor ailment." (Non-attender)

The main motivating factor for participation in the programme was a fear of the complications associated with uncontrolled diabetes, which did not seem to have been communicated as effectively to the non-attender group.

> "Well, my practice nurse, er, I mean from day one showed me photographs of these absolutely disgusting things that happen to you. It really frightened the living daylights out of me and I thought 'no, I'm going, I'm not having that'." (Participant)

Communication

Participants were initially apprehensive about attending the programme but described it as one of a "list of people to see", suggesting it had been communicated as not entirely optional. Amongst non-attenders, the voluntary nature of the programme was seen as further justification for its perceived lack of value.

> "She [practice nurse] said to me it was optional if I wanted to go or not, so I didn't do anything about it." (Non-attender)

There were a number of misconceptions about the programme amongst non-attenders; for example, some were unaware that it involved further education from the dietitian. All of those interviewed had the impression that the programme consisted mainly of exercise and for many this had been a major factor in their decision not to attend.

> "She just said there would be exercises…'bring your shorts'…I just wasn't very sure that it was the age for me to go to or not." (Non-attender)

Existing co-morbidities

A key factor in the decision not to attend the programme was the competing priorities of different illnesses. The non-attenders all had co-morbidities that they perceived to be more significant than Type 2 diabetes, including high blood pressure, arthritis, cancer, asthma, depression, back and thyroid problems.

> "To me the diabetes is a minor thing and I wasn't prepared to make the extra effort to go there… if it was going to make the angina worse." (Non-attender)

Practical considerations

There were additional concerns amongst non-attenders that the staff would not be aware of their medical history and that an eight-week course was too time-consuming.

> "It was eight weeks, it's a bit hard for me to go regularly…it would be easier to take a couple of days off work, than it would be to attend every week for eight weeks." (Non-attender)

Participants were extremely positive about the service staff and felt that both the course and individual sessions were of the correct duration. However, it was acknowledged that a longer course might result in a higher dropout rate due to lack of motivation and commitment to attend.

Perceptions of the programme

Structure and format

Participants had found the eight-week course enjoyable and felt comfortable in an informal group setting where they could ask questions, although some would have liked more one-to-one time to address particular concerns. The programme was perceived to have been well organised and provided lots of 'food for thought'.

> "They phased it nicely over the eight weeks…so we had a portion to take home and digest…And we understood that, came back and if we had any questions we could ask, and then start the next session." (Participant)

Content

The educational aspect of the sessions was greatly appreciated, as the information was felt to be useful and easy to understand. The nutritional and dietary advice was perceived to have been particularly beneficial, enabling participants to make small changes that could be maintained in the long-term.

> "The education side of it is great, it kind of tells you the benefits, it's up to you, y'know, at the end of the day." (Participant)

Impact on diabetes management

Many participants indicated that there had been significant clinical improvements in their condition. It seemed that these noticeable changes had given them the added motivation to continue leading healthier lifestyles. Strategies for diabetes management in both groups focused heavily on dietary modification, as these changes were felt to be easiest to maintain.

> "When you go [to the doctor's], your cholesterol's down, your blood pressure's down, y'know, so there's nothing else you can do really, just follow what you're doing." (Participant)

Awareness and understanding of Type 2 diabetes

Shock

The diagnosis had come as a shock to both groups. Many had been previously unaware of the severity of Type 2 diabetes and some non-attenders continued to describe it as a "minor ailment". Participants suggested this as a potential reason for non-attendance, with a perception that people remain unaware of the problems that uncontrolled diabetes can create.

> "…a lot of people aren't aware of the enormity of the problem in later life if you disregard it. I'm saying amputations, I'm saying blindness, I don't think people are aware that this could happen to them" (Participant)

Stigma

There was felt to be a kind of stigma attached to having Type 2 diabetes, although there was disagreement over whether the programme would help to remove or add to that stigma. Non-attenders described feelings of shame at having "brought the diabetes on themselves" and concern that others in the group would judge them.

> "I don't want everybody else to know I've got diabetes…it's like letting the world know, oh I'm handicapped or I'm disabled, you know." (Non-attender)

Conversely, one of the motivating factors given by participants' was as a desire to meet others 'in the same boat', to share their experiences and learn from one another.

Empowerment

Participants felt the programme had enabled them to accept and feel more in control of their diabetes, emphasising the importance of understanding that it is "a condition, not an illness".

> "I don't think I really accepted this, not disregarded it, I just thought it was something that people have. It wasn't 'til I came on this eight-week course that I realised it's a condition, and it can be addressed and looked after" (Participant)

Perceptions of exercise

Personal preference

Participants had enjoyed the exercise sessions during the course but most had not maintained increased activity levels since completing the programme, often as a result of family, work or other commitments. The preferred activity was walking but this was strongly influenced by seasonal factors such as the weather.

> "…I would say I'm more active […]Not so much in the winter, obviously because of the weather but erm, once the weather clears, I walk virtually everywhere I can." (Participant)

All of the leisure-time activities described by non-attenders could be described as sedentary.

Age-related factors

Both groups perceived gym-based exercise as being inappropriate for older adults, describing it as not personalised, interesting or stimulating enough.

> "…I know it's not right but you tend to, I tend to think of the gym as a young person's place rather than an elderly, sort of like a 60-year-old or 70-year-old people in the gym. It's, I think it's possibly not the best way to exercise when you get to that age." (Participant)

Fear

Non-attenders expressed considerable fear of exercise and perceived attendance on the programme as potentially detrimental, rather than beneficial, to their health. Individuals in both groups were concerned about over-exerting themselves, and some non-attenders were particularly uncomfortable with the idea of attending a leisure centre or exercising in a group.

> "With the angina problem I am not quite frankly capable of doing any sort of exercise…soon as they mentioned exercises and that I…no way." (Non-attender)

The general perception amongst both groups was that they were coping sufficiently on their own, particularly in the case of participants who had seen improvements in their condition and perceived that no further lifestyle changes were needed.

“We’re keeping alright as we are, I think it’s better to keep it that way.” (Participant)

Discussion

The findings of this study suggest that a programme of education and physical activity can be both enjoyable and beneficial for those newly diagnosed with Type 2 diabetes, but that there are a number of barriers and negative perceptions that need to be overcome in order to reach all of those that might benefit. The most significant barriers identified in this sample were a general lack of understanding and knowledge about the severity of Type 2 diabetes, and about the potential benefits of increased physical activity levels for all age groups. The findings of this study highlight a number of fears, concerns and misconceptions about exercise, which acted not only as initial barriers to accessing the programme but also to maintaining higher activity levels following completion of the course.

This was a qualitative study aiming to explore the views and experiences of people with Type 2 diabetes from one urban area in northern England. The small sample size and method of purposive sampling mean that the results cannot be interpreted as representative of the general population. However, due to the consistency of the findings with the results of the quantitative component of the evaluation, the researchers believe that the conclusions are robust. A validated questionnaire was used to demonstrate the lack of any significant change in participants' self-reported levels of physical activity between the start of the programme and six months following its completion. [25] However, significant improvements were observed in participants' BMI and HbA1c levels, and in their knowledge and understanding of Type 2 diabetes following participation in the programme.

Furthermore, the results of this study are consistent with the findings from the existing research literature, which have shown that many medically vulnerable adults are fearful of pain or discomfort that may occur during walking or exercise. [1] The study is also consistent with research to show that older adults are sensitive to age- and health-related changes that may make them appear inept or dependent, and may perceive that exercise is for the young. [26] The conviction that one can successfully engage in physical activity is exercise self-efficacy, which is known to be positively associated with physical activity and adherence to structured programmes. [27] The literature suggests that individualised programmes of exercise may have the greatest effect on sustained physical activity. [28, 29, 12] Physicians and other health care professionals also have an essential role to play in persuading adults to start and maintain programmes of physical activity. [1]

This research highlights the need for greater awareness raising on the severity of Type 2 diabetes amongst the at-risk population, and the need for tailored programmes of lifestyle intervention for those newly diagnosed with the condition. These programmes must take account of individuals concerns and preferences, particularly around exercise, in order to enhance both participation and maintenance of the key messages in terms of successful diabetes management. Those responsible for planning and organising the interventions should produce clear information that explains the purpose and format of the course on offer and attempts to alleviate any fears or misconceptions that potential participants might have. It is also recommended that providers explore different options for programme delivery, such as block study days, an education-only option, and a range of appropriate alternatives to gym-based activities.

Recommendations for future research include further study into perceptions of exercise amongst older adults and those with Type 2 diabetes, and also an exploration of the way that a diagnosis of Type 2 diabetes is communicated or explained to patients by different health care professionals.

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Conflict of Interest Statement

None.

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Table 1. Characteristics of Interview and Focus Group Participants

Characteristic	**Programme Participants (n =11)**	**Non-attenders (n = 10*[1])**
Mean age (range)	63 (30 to 83)	63 (42 to 87)
Male : female ratio	7 : 4	3 : 7
Employment status:-		
Employed	3 ~~(27%)~~	2 ~~(20%)~~
Retired	6 ~~(56%)~~	8 ~~(80%)~~
Permanently sick/disabled	2 ~~(18%)~~	
Socioeconomic status*[2]:-		
Affluent	Unknown	5 ~~(50%)~~
Disadvantaged		5 ~~(50%)~~

*[1] Data from two of the non-attenders in the original study sample were not considered in the analysis for reasons explained in the text.

*[2] Inferred from location of residence with regards to Index of Multiple Deprivation.

Table 2. Key Themes Arising from Interviews and Focus Groups

Major themes	**Minor themes**
Barriers to accessing the service	Diagnosis Communication Existing co-morbidities Practical considerations
Perceptions of the programme	Structure and format Content Impact on diabetes management
Awareness and understanding of type 2 diabetes	Shock Stigma Empowerment
Perceptions of exercise	Personal preference Age-related factors Fear