Patients' reasons for not attending diabetes education

The reasons patients referred to Diabetes Education programmes choose not to attend: - a systematic review

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Abstract

It is well established that diabetes education is critical to optimal diabetes care by improving metabolic control, preventing complications, improving quality of life and empowering people to make informed choices to manage their condition. Despite the significant clinical and personal rewards offered by diabetes education, programmes are underused with a significant proportion of patients choosing not to attend. This review aimed to identify the reasons those offered a place on a diabetes education programmes declined the opportunity. A systematic search of the following databases was conducted; Medline, Embase, Scopus, CINAHL and PsycINFO from 2005-2015. Studies that met the inclusion criteria focusing on patient-reported reasons for non-attendance at SDE were selected. A total of 12 studies spanning quantitative and qualitative methodologies were included. The selected studies were published in Europe, USA, Pakistan, Canada and India with a total sample size of n = 2260. Two broad categories of non-attender were identified: 1. Those that could not go due to logistical, medical or financial reasons (e.g. timing, costs, existing comorbidities etc). 2. Those that would not go due to a feeling of there being no perceived benefit, feel they have sufficient knowledge already or emotional and cultural reasons (e.g. no perceived problem, denial, negative feelings towards education). Diabetes education was declined for many reasons and the range of expressed reasons was more diverse and complex than anticipated. New and innovative methods of delivering diabetes education are required which address the needs of people with diabetes whilst maintaining quality and efficiency.

Introduction

With the world prevalence of diabetes increasing every year [1], efforts to promote diabetes education and self-management are critical to reducing the human and economic burden of this condition. High-quality structured diabetes education plays a fundamental role in improving self-management and subsequently metabolic control [2]. Evidence shows that, with reinforcement, these benefits can be maintained and can have positive effects on quality of life and health outcomes [3]. Improving knowledge, skills and confidence enables patients to take more control of their own condition and integrate effective selfmanagement into their daily lives [2,4,5]. Boren *et al.* (2009) [6] concluded that the benefits associated with diabetes education are positive and outweigh the costs associated with the intervention. Furthermore, it has been demonstrated that patients who did not attend any form of diabetes educational intervention had a four-fold increased risk of developing complications [7].

Diabetes education has evolved in the last fifteen years from a mainly local, ad hoc approach that was rarely underpinned by empirical theory to one in which substantial efforts have been made to ensure that diabetes education is evidence based, theory driven, delivered by trained educators, quality assured and regularly audited [8,9]. NICE guidance states that patient education programmes should meet the cultural, ethnic, linguistic, cognitive, geographical and the literacy needs of the locality. In addition all members of the healthcare team need to be familiar with the programmes available locally and these programmes must be integrated within the diabetes care pathways [8,9].

Despite the demonstrable benefits of diabetes education, [2,4,5], the programmes offered are underused with a significant proportion of the diabetes population not engaging either

by declining outright when invited to participate or by initially agreeing but then never attending.

A recent national audit in the United Kingdom (UK) [10] reported that of those diagnosed with Type 1 diabetes, education was recorded as being offered to only 2.4% of which only 1.1% were recorded as attending. Similarly in those with Type 2 diabetes 6% were recorded as being offered diabetes education of which only 1.6% was recorded as attending. In those newly diagnosed with diabetes the figures are only marginally better with 3.9% of people with Type 1 and 16.7% of people with Type 2 recorded as being offered education with only 0.9% and 3.6% respectively attending [10]. The problem of low referral rates to diabetes education, followed by a lack of uptake, appears to be of global concern. It is estimated that between 30% and 93% of eligible patients' do not to attend diabetes education with these figures varying widely within and accross countries [11,12,13,14]. In addition, a recent multinational study assessing psychosocial outcomes in people with diabetes showed that only 48.8% had participated in any form of educational programme. This ranged from as high as 84% in Canada to as low as 23% in India [15].

These figures are particularly concerning given the results of a recent study amongst children and adults with Type 1 diabetes conducted across 19 countries which revealed that the majority of people with Type 1 diabetes did not achieve the recommended HbA1c target of 48mmol/mol-58mmol/mol (6.5-7.5%), with 15-24 year olds having higher levels than any other age group, predisposing them to future health problems [16,17]. This is of particular concern as young people with Type 1 diabetes are face a lifetime of diabetes self-management. Although considerable progress has been made across the UK with regards to meeting clinical targets in the management of Type 2 diabetes [18] this is likely to be due to

the system of treating to target in general practice [19] rather than improved selfmanagement.

Many reviews published in the area of diabetes education focus on its effectiveness [2,4,20,21], on attrition from programmes [22] or on psychosocial outcomes [23]. One recent review [24] did focus on barriers to attendance in diabetes education centres, however, the review included studies of patients who initially attended then subsequently dropped out of diabetes education, studies that reported healthcare professionals suggested reasons for patients' non-attendance and papers reporting the characteristics of those who did not attend. The current review is the first to focus exclusively on patients' expressed reasons for not attending diabetes education programmes.

The aim of this review is to identify the expressed reasons why patients offered a place on a diabetes education programme declined the opportunity. The findings will inform diabetes service providers, educators and commissioners of potential opportunities that may enhance uptake.

Methods

A systematic review of the literature on patients' expressed reasons for non-attendance at diabetes education was undertaken using PRISMA guidelines [25].

Data Sources and Searches

Five-electronic databases (CINHAL PLUS, EMBASE, Medline, Psychinfo and SCOPUS) were searched for the period January 2005 – June 2015. The search criteria used the following keywords or a combination of these keywords: "diabetes mellitus"; "Type 1 diabetes";

"Type 2 diabetes"; "diabetes patient"; "diabetes education"; "group education"; "structured diabetes education"; "self-care; patient participation"; "patient education"; "education programme"; "refusal"; attendance"; "non-attendance"; "non-adherence"; "barriers"; "attrition"; "declining" and "disparities". Other studies were identified by manually searching reference lists of retrieved papers. The eligibility criteria for inclusion were: (1) Original research; (2) The patient sample of each study must have expressed clear reasons why they could not or would not attend SDE; (3) Published in the year range 2005-2015 (4) In the English language; (5) Full text articles.

Those studies that only reported the demographic characteristics of non-attenders rather than their expressed reasons were not included in this review, nor were those studies in which only physicians and/or educators gave their perceived reasons for patients' nonattendance. Studies reporting data on people who had partly attended and/or dropped out of structured diabetes education programmes were also excluded.

Data Extraction and Analysis

Twelve studies met the inclusion criteria and were included in this review (summarised in Table 1). Relevant data (i.e. expressed reasons given by the patient for non-attendance at diabetes education) were extracted (using a data extraction sheet developed by two of the authors GH and VC) by four of the review authors GH, FFW, DC and VC. Any differences in opinion were resolved through discussion. An iterative process was employed to review each study and an inductive methodology for thematic analysis applied to elicit patient specific reasons for not attending diabetes education.

Results

A total of 2073 titles and abstracts were retrieved and screened for eligibility by one researcher (GH). After removing duplicates, n = 683 articles were identified. This number included 8 hand-searched publications from reference lists. Of those citations n = 657 were excluded based on title, abstract or full text content. The quality of the remaining 26 articles was appraised using the McMaster University critical review forms for quantitative and qualitative studies [26,27]. After consensus on eligibility was agreed by two researchers (GH and VC) a total of 12 studies spanning qualitative and quantitative methodologies were included in this review (Figure 1).

The studies varied in terms of design, five were of a qualitative nature [11,28-31] and seven were surveys [12,13,32-36]. Studies were conducted across six countries (Table 1): United Kingdom 3 [12,29,30], Germany 2 [11,32], India 1 [34], Pakistan 1 [31], USA 3 [28, 35,36] and Canada 2 [13, 32]. Ten of the studies were conducted in primary care or community settings [11-13,28-30,32, 33,35,36], one was set in a hospital out patients department [31] and one was set in a tertiary care diabetes centre [34]. The education programmes offered were mainly to those with Type 2 diabetes, however four of these studies also included programmes offered to people diagnosed with Type 1 diabetes [31,33,35], those with pre-diabetes [33] and one study included two participants who were representing their husbands [28]. Seven of the studies included data provided by a combination of programme participants and non-participants [13,28-32,35], one included data from participants, non-participants, educators and physicians [35] and one included non-participants, educators and education providers [36]. For the purpose of this review it was the specific reasons

given by those patients who did not attend diabetes education that were extracted and reviewed.

Across the 12 studies n = 2,260 (see Table 1) gave specific reasons for choosing not to attend diabetes education. Seven studies reported the age range of non-attenders which spanned from 18-87 years [11,13,28-32], two studies reported mean age only which was 54 and 55 years [34,35], two studies did not report age [12,36] and one study combined ages of attenders and non-attenders [33]. Of the eight studies that reported gender [13,28,31-35], 80% of non-attenders were male.

Two studies reported non-attenders to be younger, to perceive their condition as not serious or coming from higher socio-economic and income groups [13,32]. One study found non-attenders to be older [36]. In contrast one study found no difference in age, found that non-attenders were less likely to have graduated from school and were more likely to be unemployed [34]. One study found no differences in attenders and non-attenders in respect of HbA1c, blood pressure or body mass Index [32].

Five studies presented qualitative data derived from either semi-structured interviews [11,29-31] or focus groups [28]. Topic guides focused on the various aspects of living with diabetes [31], reasons for non-attendance, knowledge of diabetes, quality of life, medical background [30], preferred education/learning approaches, barriers to attendance [28], attitudes to diabetes and knowledge of diabetes education [13]. The seven quantitative studies investigated expressed reasons why people choose not to attend diabetes education, the barriers influencing attendance and factors relating to access using self-developed, study specific questionnaires [12,13,32-36].

Across the 12 studies, thirty-six separate reasons for non-attendance at diabetes education were expressed with the most frequent being: issues with timing and/or length of courses, access/transportation issues, family and work conflicts, lack of information on what the course entailed, benefits of attending not conveyed by health care professionals, patients perceiving that they already had sufficient information to self-manage their condition and contentment with information received from their GP or diabetes team.

Thematic Analysis

Two overarching themes expressed by people who chose not to attend diabetes education emerged (Table 2).

Those who could not go

For those who reported they could not attend diabetes education, their reasons could be sub-grouped into three broad categories:

- Logistical- Lack of time, transport issues, the venue was felt to be too far away, no parking at venue. Programmes were felt to be too long or scheduling of programmes was unsuitable. More pressing commitments such as work and family were prioritised over diabetes education.
- Medical- Physical disabilities or other illnesses prevented attendance or unable to attend alone.
- Financial- Insufficient health insurance cover or unable to afford travel and/or costs associated with getting to venue.

These issues are illustrated in quotes reported by qualitative studies:

"It was eight weeks' it's a bit hard for me to go regularly...it would be easier to take a couple days off work than it would be to attend every week for eight weeks [30]."

"No parking.....so you're talking an hour and a half on the bus [29]."

"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" [30].

"Because I work nights, because my wife is disabled, I haven't even got time to go to the foot clinic. The answer would be no" [28].

"The time, work, the car, my kids" [28]

Those who will not go

The reasons for non-attendance given by those who stated that they won't go can be grouped into four broad categories.

- No perceived benefits- Some people perceived they would not benefit from attending diabetes education, or it was not seen as high priority. Lack of enthusiasm shown by the health care professionals who invited them influenced decision not to attend and some felt there was no need to attend because they were satisfied with the care they were already receiving.
- **Knowledge** Some felt they knew enough already, or that they had received enough information about diabetes from other sources. Some people also reported their

opinions were influenced by a lack of information and a number felt there was no need to be educated because they did not perceive they had a problem.

- Emotional- People reported feeling negative towards diabetes education or feeling uncomfortable about the idea of joining a group. Some also acknowledged that they preferred not to know about complications of diabetes because they would become anxious, and some were scared that they could not cope with the demands of an education course. A number also cited denial or said they did not want anyone to know they had diabetes.
- Cultural- Literacy, language and cultural issues were also cited.
 Some of these issues are illustrated in quotes reported by qualitative studies:

"I have 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 ailment" [30]

"She (the practice nurse) said to me it was optional if I wanted to go or not, so I didn't do anything about it" [30]

"As long as my blood sugar is not too high...No, I would not yet attend it [patient education]. Unless it was rising, then I suppose I ought to attend it" [11]

"I think I prefer one to one, I don't think I prefer the group at all…I think it is erm, you know, you in a group of strangers with people you've never met before. I don't think I'll like it [29]."

"I don't want everybody else to know I've got diabetes...it's like letting the world know, oh I'm handicapped or disabled, you know [30]."

"Classes should be arranged for people like yourself (educated) but not for us (illiterate) it will not hold any benefit [31]."

Discussion

The purpose of this systematic review was to identify and explore the reasons so many people with diabetes choose not to attend diabetes education programmes. Our findings suggest there are a multitude of reasons why patients "cannot" or "will not" attend diabetes education. The reasons given are more diverse and complex than anticipated.

Of the studies that reported the characteristics of non-attenders compared to attenders the results were conflicting, making it difficult to reach a reliable conclusion [13,32,34]. Of note however are the studies that did report on gender [13,28,31-35], 80% of the non-attenders were male. It has previously been shown that diabetes education needs to be targeted differently to men and women [37]. There were differences across the six countries in terms of referral of patients to diabetes education. Despite whether or not attendance is made a compulsory element of statutory health insurance, differences in the costs of programmes and in health insurance rates, differing levels of illiteracy, cultural issues and the degree to which programmes were structured, many reasons for non-attendance were similar across the three continents. Many of the included studies, irrespective of country, discussed patients' already having sufficient knowledge, physicians not providing sufficient information, and family and friends being a source of knowledge as reasons for non-attendance at diabetes education [11,12,13,31-33,35,36]. It has been suggested that if a

patients' clinical results and diabetes knowledge are good then non-participation may be a justified decision [11].

Those attempting to improve rates of attendance should bear in mind that tackling one or two issues will still leave many others unaddressed and it has been demonstrated that rescheduling programmes within community settings, holding programmes at different times of the year and of the day and costs being fully compensated by health insurance companies or programmes offered free of charge does not significantly increase uptake [2,11,28].

Nonetheless some recommendations can be made. The need to effectively promote and market all aspects of diabetes education was highlighted by the majority of the included studies [11,13,29-34,36]. When non-attenders were given more information about diabetes education many said they would be willing to attend or expressed a wish to receive more information [13].

Marketing is not a skill typically associated with healthcare professionals or healthcare services but diabetes education could be seen as a product which would benefit from an effective marketing campaign. Too many people are simply rejecting educational opportunities without fully understanding what is involved and what they might gain from attending. In addition a recent All-Party Parliamentary Group report (APPG) [38] highlighted that online resources and support groups were highly rated but patients were not being directed to them by healthcare professionals.

A report from the Department of Health patient education working group found gaps in the support needs of vulnerable groups such as people with language and literacy problems,

people with learning difficulties and difficult-to-reach groups such as travellers, refugees and asylum seekers. They identified that innovative approaches to diabetes education may be needed to reach these groups and suggested a variety of techniques that could be used, such as picture charts, video techniques, cartoon-based learning, text messaging and the use of e-mail tailored to the group or individual [39]. In addition an evaluation of a mobile, diabetes care, telemedicine clinic serving indigenous communities found that it improved access and was also cost-effective [40]. This method if adapted could significantly improve uptake of education in both urban and rural communities. It has also been suggested that diabetes 'burn out' which can lead to disengagement can affect uptake of education and that by offering peer support with patients who have attended education may be useful in re-engaging those who have become hard to reach [38]. While the evidence on peer support in health promotion is conflicting [41] it does appear to be effective in high risk populations [42].

Funders, educators and commissioners' need to think of ways in which diabetes education can be redesigned, marketed, timetabled and delivered whilst taking into account the views of those who have effectively rejected this product. Declining diabetes education is not a new problem and similar reasons for non-attendance were reported more than 25 years ago [43]. Given the results of the recent National Diabetes Audit, lessons have clearly not been learnt [10]. As it is impractical to provide one to one diabetes education to all or offer programmes on everyone's doorstep, other modes of delivering diabetes education to compliment what already exists are recommended. Evidence has shown that providing diabetes education programmes via video/DVD may be just as effective as group education [44-45] and Holmes et al (2012) demonstrated increased knowledge and change of attitudes

in women with gestational diabetes using an educational DVD [46]. Similarly, patients using a clinic based touchscreen computer system designed to assess health behaviours showed improvements in both dietary intake and cholesterol levels compared to those who did not use it [47]. A structured education programme targeted at those with Type 1 diabetes and delivered online with supplemental tutorial time was shown to increase accessibility, improve HbA1c and quality of life [48]. Such technology, if adapted and made available on mobile smartphones and/or as applications, could overcome many of the obstacles identified in this review including cultural, gender, literacy and language barriers. In addition such technology could be accessed anytime, anywhere at the users own pace and made available to large numbers of patients at minimal cost.

Several studies have reported patients' opinions on how they would like to receive information and in addition to telephone, computer websites, email, internet, books, CD, videos or DVD's other suggestions included supermarket tours, cooking classes, physical education classes and information from peers [36,49]. Recent evidence has demonstrated that being a member of an online diabetes forum resulted in reduced HbA1c levels, improved glucose control, improved dietary choices and a better understanding and increased confidence in managing diabetes [50].

It would appear to the authors that in the last 10 years efforts to improve structured diabetes education have, for very good reasons, focused on curriculum content and quality assurance. Unfortunately ideas about how to fit diabetes education with the needs, beliefs and lives of people with diabetes have received less attention. A slightly more individualised, patient centred approach is probably required if uptake is to be enhanced.

Quality Appraisal

Of the twelve studies reviewed, seven were quantitative and five were qualitative in methodology. Only six reported that research ethics approval and/or patient consent was obtained. Design and methods were explained clearly, and would be replicable in most of the studies. Limitation in sampling was an issue in three of the qualitative studies. Francis et al (28) presented findings from one focus group with five participants. Whilst generalisability of findings is not the aim of qualitative studies, it is important that there is confidence that a degree of saturation in themes arising from the data has been reached. A sample of five would be unlikely to generate sufficient data to enable confidence with regards to saturation. Two other qualitative studies by Visram et al [30] and Rafique et al [31] used face to face individual interviews. Similar to the study by Francis et al [28] the principle of data saturation was not discussed. However, methods to ensure rigour were outlined, such as member checking in the coding of the data, and triangulation in data analysis.

Strengths and limitations

This review identified papers published in English language in the year range 2005 – 2015. It is possible that the inclusion criteria may have excluded pertinent literature published outside of this year range and in a language other than English. A total of 12 papers were identified. Limitations in the published papers were outlined. These mainly pertained to inadequate reporting of research ethical approval processes and inadequate explanation of sampling decisions. Of particular concern is the inconsistent or absence of demographic and other characteristics of those who did not attend education programmes and this hampers attempts at future meta-analysis. Given that extensive funding is involved in commissioning diabetes self-management education programmes, this review indicates the need for robust

research to be undertaken pertaining to the value, benefits, attendance and attrition issues of such programmes,

Conclusion

Those who deliver diabetes education will recognise that too often there is a mismatch between priorities, needs and capabilities of the person referred and the delivery of the education course. Referrers therefore bear a heavy responsibility for ensuring that those who are referred are appropriate, ready and fully informed whilst those who provide education should ensure their courses are accessible in time and place wherever possible. The relationship between referrer and provider is therefore a crucial one. Perhaps the biggest challenge is how to make patient education more patient centred. The need for diabetes education to be curriculum (rather than patient) centred and for it to be usually commissioned and delivered in group settings promotes quality and efficiency but mitigates against flexibility to patient circumstances and needs.

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Competing Interests

None

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Patients' reasons for not attending diabetes education

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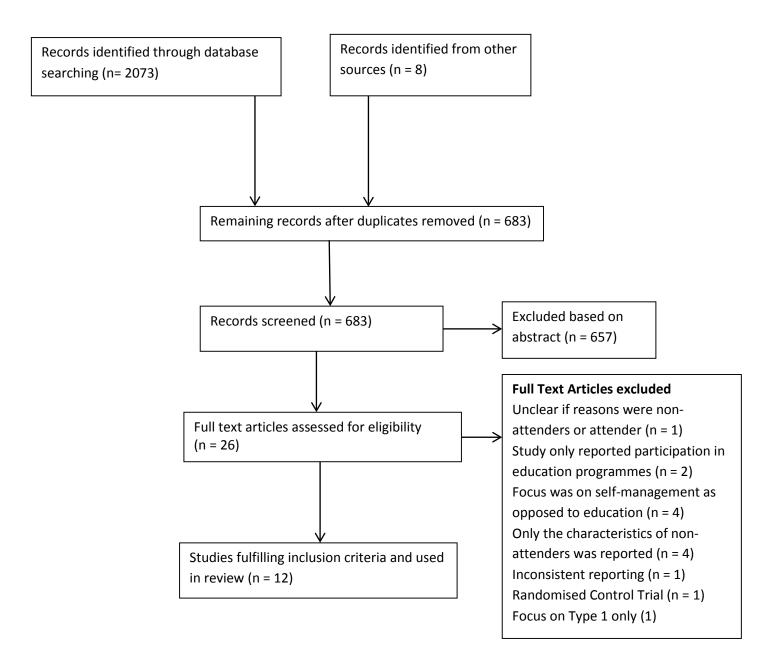
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Figure1. Flow diagram to show results of searches for systematic review.



Author, year published and setting	Study period, design & purpose, selection of cases, methods of data collection	Cost of programme to patient	Non- attendees only	Outcomes, results	Limitations
Francis et al, (2014), USA [28]	No study period reported. Qualitative study which aimed to examine the factors that influence low participation rates in a Latino community based diabetes education programme. n = 5 participants who initially expressed an interest in the revised Dining with Diabetes (DWD) education programme (adopted by 6 US States as it has been shown to reduce HbA1c levels) were invited and asked to complete a socio-demographic and diabetes self- management questionnaire and participate in a 1 hour focus group which among other topics included barriers to attendance. The focus group was conducted in Spanish, recorded, transcribed and analysed for common themes. General descriptive statistics were used assess questionnaire responses.	DWD education programmes are provided at a low or no cost (for this particular programme there was no cost). Insurance is not required for people to attend the programs.	(n = 5)	Reported barriers for non- attendance at the Dining with Diabetes programme included limited time, family and work conflicts, viewing DWD as a low priority and access issues. In addition limited use of culturally preferred marketing was seen as a barrier.	Small sample size of one small focus group. Ethical approval not discussed however, consent was obtained from participants.
Winkley et al, (2014) United Kingdom [29]	2008-2011. Qualitative study of a purposeful sample of non-attenders (n = 30) from a previous study in South London by the same authors which had recruited a cohort of people newly diagnosed with Type 2 diabetes who were offered DESMOND Programme. The aim of this study was to examine key themes for non-attendance (which is as high as 65%) at structured diabetes education using semi-structured interviews. Patients were sampled according to their age (3 age groups ≤ 45 years, 46-59 years and 60 years), gender, self-reported ethnicity and borough of	No cost	(n = 30)	Three main themes emerged explaining reasons for non- attendance at structured diabetes education. 1) Lack of information/perceived benefit of programme, 2) Unmet personal preferences (e.g. parking, timing) and 3) shame and stigma of diabetes (appeared to be a cultural issue).	Participants were coded as non-attenders if they had no recollection of being informed of diabetes education.

Table 1. A summary of the study characteristics and main findings of the articles included in the systematic review.

	residence in South London. A thematic				
	framework method was applied to analyse the				
	data.				
	2010. Qualitative study, aiming to examine	Fully		12 reasons for non-participation	Only participants from the city included,
Schäfer et al,	patients' attitudes towards diabetes education in	compensated	(n = 14)	in diabetes education were	therefore reasons from rural dwellers not
(2014) Germany	order to identify the barriers as to why ≈ 30-50%	by German		identified that fell into 4	addressed.
[11]	do not participate. n = 18 adult patients	Statutory		themes: Physician's influence,	
	diagnosed with Type 2 diabetes who had enrolled	Health		State of health condition,	
	in a disease management programme and who	Insurance		Avoidance and refusal,	
	had no prior attendance at a diabetes education			Knowledge and activity.	
	course were contacted from purposively selected				
	GP practices and partook in semi-structured face				
	to face interviews. Interviews were audiotaped.				
Schäfer et al,	2009. Cross-sectional, observational study aiming				Small sample size for a quantitative study.
(2013) Germany	to describe patient-reported reasons for	Fully	(n = 132)	4 typical subgroups of	
[32]	nonparticipation in diabetes education and to	compensated		nonparticipants were identified;	
	identify subgroups of non-participants in order to	by German		The informed and responsible,	
	improve recruitment strategies. n = 297 adult	Statutory		the unconcerned without desire	
	patients diagnosed with Type 2 diabetes who	Health		for more information, the	
	were either participants or nonparticipants in	Insurance		uninformed but responsible and	
	diabetes education were randomly recruited			the anxious and burdened with	
	from 30 primary care practices in Germany.			psychosocial problems and	
	Exclusion criteria were a diagnosis of Type 1			functional limitations. The main	
	diabetes and aged ≥ 80 years. All recruits			actual reasons given by non-	
	completed a patient health questionnaire and			participants for not attending	
	comparisons were made between 165			diabetes education were that	
	participants and 132 non-participants.			they already considered their	
				knowledge of diabetes to be	
				sufficient, felt diabetes	
				management is the	
				responsibility of their physician,	
				Other reasons included negative	
				feelings towards education and	

				groups, the purpose of course being unclear, physical demands and difficulty of the course, vision and hearing problems, timings of classes, distance from venue and financial issues were also indicated as reasons for non- attendance.	
Gucciardi et al, (2012) Canada [33]	2008. Internet based survey. This study aimed to explore patient utilisation of and barriers to attending diabetes education centres (DEC). n = 221 adult patients diagnosed with either Type 1, Type 2 or pre-diabetes were recruited via an internet survey. All participants completed a questionnaire either online or a hard copy and data were subjected to a mixed method analysis.	Funded in whole or in part by the Ministry of Health	(n = 62)	The most common reasons for participants never attending the diabetes education centre included already receiving education from their GP, lack of information about diabetes education courses from their GP, feel they have enough information and support to self- manage their diabetes, inconvenient scheduling, too ill, access issues, language issues and long waiting lists.	Small sample size for a quantitative study, limited to a small region of Ontario, Canada. Attenders and non-attenders characteristics combined. No ethical approval or consent was discussed.
Shaji et al, (2012) India [34]	No study period reported. Cross-sectional study which selected patients attending a tertiary care Diabetes Centre for both, first visit or review (after an absence of more than 1 year). All subjects (n = 756) presenting at the hospital for a non-acute visit were included in the study irrespective of their attendance at diabetes education. The study aimed to understand the bias and barriers influencing the poor attendance rates of patients towards diabetes education	Not specified	(n = 540)	The main barriers to attendance as reported by the non- attenders were lack of time or no time and not interested. Problems with reading due to eyesight complications in addition to hearing problems and stress. Main perceived barriers to	Neither ethical approval nor patient consent reported.

	programmes. A survey questionnaire was used to collect information on demographics, clinical factors associated with diabetes, predictors of attendance at diabetes education programmes using both closed and open ended questions. Responses to open ended questions were recorded verbatim by the researchers. All other data were analysed using SPSS.			diabetes education were: - Repetition of content, lack of time, no interest, don't care, denial, unaware of resources and a combination of the above reasons.	
Wadher, (2010) UK [12]	2010. Postal survey, which selected the last (n = 200) patients (100 newly diagnosed with diabetes and 100 with established diabetes) who had not responded to an invitation to attend a DESMOND programme. The aim of this service review was to ascertain why such a high percentage (65%), choose not to attend the DESMOND programme and whether the programme could be altered to accommodate more of these people. All 200 patients were posted a short anonymous multiple choice survey designed to address the aim. Descriptive statistics were used to describe reasons for non-attendance.	No cost	(n = 47)	The main findings of this survey for non-attendance at the DESMOND programme were; Timing of programme, already knowledgeable, venue, length of course, no referral letter received, dislike of groups, no reason given and access issues.	Small sample size for a quantitative study did not report patient characteristics nor reported on ethical approval or consent.
Peyrot et al, (2009) USA [35]	No study period reported. Internet based survey. This study aimed to investigate factors associated with access to Diabetes Self-Management Education (DSME) the perspective of not only the patient (n = 1169) but also the educator (n = 1871) and physicians (n = 629). With respect to the patient group only n = 508 adult patients diagnosed with both Type 1 and 2 diabetes who had never attended a DSME programme completed an online questionnaire which aimed	Not specified however, The Affordable Care Act (ACA) in the USA is intended to help all Americans have health insurance, but to what extent	(n = 503)	The main patient barriers to DMSE self- reported by those patients who never attended were:- Don't think they need education, can't fit into schedule, insurance issues, financial issues and access issues.	Minorities and those from lower socioeconomic backgrounds were under-represented. Did not report ethical approval for study.

	to assess barriers to access. All data were	that insurance			
	analysed using SPSS.	covers			
		diabetes			
		education			
		varies greatly			
Temple et al,	2003-2004. Cross-sectional descriptive approach	No cost	(n = 62)	The most common reasons	Limited to a rural region of Western
(2009)	was employed to evaluate demographic and			cited for non-attendance were:-	Canada. Small sample size for a
Canada	other characteristics of attendees and non-			Being too busy, transportation	quantitative study.
[13]	attendees at a diabetes/heart health educational			issues, felt other health issues	
	program. A random selection (n = 124) out of a			more important, difficulty	
	possible 671 were administered a telephone			getting time off work, felt their	
	questionnaire which was designed by the authors			Doctor was enough to manage	
	to determine perceived barriers to attendance at			their diabetes, felt they did not	
	the Prairie Health Matters Education Programme			need help, didn't see the	
	Bivariate statistics- Chi square or t-tests were			benefits, forgetting, difficulty	
	used to identify significant differences in			getting an appointment and	
	demographic and other characteristics between			never hearing of the service.	
	attendees and non-attendees using SPSS version			Non-attendees were more likely	
	15.			to be younger, have a higher	
				income and work full-time.	
Visram et al,		Free	(n = 10)		Purposive sampling method may not be
(2008)	No study period reported. This qualitative study		· · · /	The most significant barriers to	generalisable.
United Kingdom	used a purposeful sampling strategy to select (n =			attendance at this education	
[30]	12) non-attenders aged from (42-87 years) from			and physical activity programme	
[]	an earlier study. Participants were interviewed			was a lack of awareness of the	
	using topic guides developed in conjunction with			severity of diabetes, perception	
	the diabetes nurses. This study aimed to explore			of education being voluntary	
	factors affecting uptake of 'The Newcastle			therefore of not much value,	
	Education and physical activity programme for			not being fully aware of what	
	Newly Diagnosed Type 2 Diabetes'. Non-			programme entailed or who	
	attenders (50%) to the programme were invited			would be involved, co-	
	on to the study by letter from their GP. The			morbidities felt to be more	
	interview probed their medical background,			significant than their diabetes,	
		1	1	0	1

	quality-of-life, knowledge of diabetes and reasons for non-attendance. Data were analysed using a thematic content/framework			that staff would not be aware of their medical history, programme too long and a	
	approached.			considerable fear of exercise.	
Rafique et al, (2006) Pakistan [31]	No study period reported. Exploratory, descriptive research design was employed to identify care and education issues among persons with diabetes in Karachi and to assess the knowledge, educational needs around their diabetes and their willingness to learn. A qualitative approach using semi-structured questionnaires was used. n = 27 participants (11 men) and (16 women) diagnosed with either Type 1 or 2 diabetes and aged ≥ 18 years were randomly selected from a larger study, all were Pakistani nationals who had attended out-patient clinics.	Not specified	(n = 14)	The main themes pertinent to education were: Doubt about its usefulness, fear of being overwhelmed and being unable to understand what is being communicated and using family and friends to gain knowledge. With the specific reasons given by those who were not interested in attending diabetes education being:- Living too far away from the hospital, unable to come alone, no free time i.e. other commitments.	Does not describe ethical approval however consent from was obtained from participants.
Maine Dept of		Not specified,	(n = 841)		Did not report statistical methods used
Health and	2005-2006. The Maine Diabetes Prevention and	however cost		Maine Care members reasons	nor did they report patient characteristics
Human Services,	Control Programme Centre for Disease Control	was not listed		for not attending diabetes	or ethical approval.
(2006)	(Maine CDC DPCP), conducted surveys of primary	in the top five		education were dislike of group	
USA	care providers, diabetes educators and patients	barriers to		education, not interested, felt	
[36]	with diabetes to determine barriers to referral	attendance		they did not need information,	
	and participation in self-management	and the		unaware of the education,	
	programmes. With respect to the diabetes	information		transportation issues, timings,	
	patients only, individuals diagnosed with	was provided		too busy, difficult to	
	diabetes and registered with either a commercial	by health		understand, not convenient,	
	(Maine Care Program) or public funded (Anthem	insurance		classes too long and having to	
	health-insurance programme) were administered	programmes.		wait too long.	
	a survey to measure their experience with Diabetes Self-Management Education (DMSE) the			Anthem members reasons for	

survey included the topics of barriers and needs	not attending education were:
to DMSE. n = 2720 responded to the insurance	felt they could manage on their
providers survey of those (n = 841) reported they	own, timings not convenient,
did not attend Diabetes Education. The analysis	don't need information, too
was conducted by the Muskie School of Public	busy, don't like groups, no
Service however, the methods used nor patient	insurance/too expensive, need
Characteristics were not reported.	more info, not interested, info
	doesn't meet needs,
	transportation issues and
	having to wait too long.
	Therefore 2 themes emerged.
	Consumer perceptions, access
	issues
	to DMSE. n = 2720 responded to the insurance providers survey of those (n = 841) reported they did not attend Diabetes Education. The analysis was conducted by the Muskie School of Public Service however, the methods used nor patient

Table 2. Themes, categories and reasons that emerged in review.

Overarching themes	Categories of reasons	Reasons
Those who could not go	Logistical reasons	 -Lack of transport -Venue too far away -No parking at venue -Length of programmes -Timings of programmes unsuitable -More pressing commitments e.g. family and/or work
	Medical reasons	-Other disabilities or illnesses preventing them from attending SDE. -Unable to come alone
	Financial reasons	-Not having any or insufficient health insurance cover -Unable to afford travel and/or costs associated with getting to venue.
Those who will not go go	No perceived Benefit	 -Feel there is no perceived benefits to be gained -Not seen as high priority. -Physicians Influences. -Already satisfied with care receiving
	Knowledge	 -Know enough already -Feel they already receive adequate information from physician/GP -Feeling there is no need to be educated as they don't perceive a problem. - Lack of information on programmes -Unaware of available programmes -Programmes not promoted by health care professionals.
	Emotional	-Negative feelings of diabetes education -Negative feelings of groups -Don't want to know side effects of diabetes. -Fear of excessive demands. -Denial -Don't want anyone to know.
	Cultural	-Literacy /language/cultural problems -Those with no reason/not interested and/or don't know why they won't go.