

# Factors influencing attendance at structured self-management education programs for diabetes

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## ABSTRACT

**Aims:** There are several structured self-management education programs which are available nationally for patients with diabetes in the UK. This study was aimed to determine the factors influencing participation of patients with diabetes in the programs.

**Patients and Methods:** A cross-sectional survey through semi-structured questionnaire distributed to 550 patients attending primary or secondary care diabetes services, as well to those in community venues, was conducted. The inclusion criteria were people  $\geq 18$  years with diabetes diagnosed for 1 year or longer.

**Results:** There was a lack of awareness of the programs among the respondents. There were statistically significant differences between tendency to attend the programs with demographic variables, qualification, and self-efficacy. The results also indicated that an individual will be more likely to participate in the structured self-management education programs if she/he feels at risk of complications, that diabetes complications are serious, and believes that the programs may help to avoid these risks.

**Conclusions:** This study indicated the nature of multidimensionality of the factors influencing participation in the programs.

**Key words:** Diabetes, participation, self-management education programs

## INTRODUCTION

Globally a worrying increase in the number of people who suffer from diabetes has been seen in the past two decades. Diabetes mellitus is now taking its place as one of the important threats to human health in the 21<sup>st</sup> century. It is a major public health challenge associated with significant morbidity and mortality. It is estimated that about 171 million people in the world live with diabetes, and this is expected to increase to 366 million by 2030. In the UK, the number of people living with diabetes is continually rising.<sup>[1]</sup> The nature of diabetes management is based on self-management in which patients need to manage their disease on a day-to-day basis.<sup>[2]</sup> It requires the acquisition of a range of skills including exercise, dietary management, foot care, blood glucose testing, and medication therapy.<sup>[2,3]</sup>

Policy-makers have also focused on promoting structured self-management education (SSME) programs as a cost-effective approach to improving health outcomes and as an integral part of optimal diabetes care.<sup>[4]</sup> National Institute for Health and Clinical Excellence recommends

that all patients with diabetes in the UK should be offered an SSME program at the time of diagnosis.<sup>[5]</sup> There are currently three specific formal and national types of SSME programs for patients with diabetes, including Diabetes Education and Self-Management for Ongoing and Newly Diagnosed (DESMOND)<sup>[6]</sup> and Expert Patient Education versus Routine Treatment (X-PERT) program<sup>[7]</sup> for people with type 2 diabetes and Dose Adjustment For Normal Eating (DAFNE) for people with type 1 diabetes.<sup>[8]</sup> The programs are designed to improve disease-specific knowledge related to diabetes, and aim to help patients overcome common problems associated with living with diabetes. The programs include a blend of educational, behavioral, and/or psychological components delivered as a mix of didactic and interactive formats to a group over several sessions. Table 1 shows a summary of the topics covered in the programs.

Despite the established benefits of SSME for diabetes, such as improving metabolic control, quality of life, and preventing complications,<sup>[7-9]</sup> the results of a national survey indicated that only 11% of patients with diabetes had attended an education or training event.<sup>[10]</sup> Although identifying barriers and levers to participation is a necessary first step in addressing these low attendance rates, factors that influence patients' decisions to participate and to continue or discontinue the use of the SSME programs are ill-defined. Accordingly, the main aim of this research was to determine such factors influencing participation of patients in SSME programs (e.g. the level of awareness, self-efficacy) in patients with diabetes.

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**Table 1: Comparison of topics covered in the structured self-management education curriculum**

Content	Desmond	X-PERT	DAFNE
	T2DM	T2DM	T1DM
Goal setting	✓	✓	
What is diabetes?	✓	✓	✓
Weight management and energy balance	✓	✓	
Carbohydrate awareness	✓	✓	✓
Reading and understanding food labels (supermarket tour)	✓	✓	
Available resources and X-PERT game		✓	
Complications of diabetes	✓	✓	✓
Nutrition in diabetes	✓	✓	✓
Physical activity and diabetes	✓	✓	✓
Medication in diabetes	✓	✓	✓
Adjusting insulin dose approach			✓
Metabolic control			✓
Monitoring diabetes and annual review	✓	✓	✓
Stress and emotions in diabetes	✓		
Anger/fear/frustration			
Depression	✓		
Better breathing			
Fatigue management			
Cognitive techniques			
Communications			
Problem solving	✓		

DESMOND, Diabetes Education and Self-Management for Ongoing and Newly Diagnosed; X-PERT, Expert Patient Education versus Routine Treatment; DAFNE, Dose Adjustment for Normal Eating; EPP, Expert Patient Program

## PATIENTS AND METHODS

A cross-sectional retrospective survey was adopted to elicit responses from patients with diabetes about the programs. The research method used in this study is discussed in this section.

### Patients

All respondents were recruited using a convenient sampling from two large teaching hospitals, four general practices, and a number of community venues (e.g., gym, mosque to recruit further ethnic minority patients) in Leeds. The aim of this strategy was to obtain a mix of participants to obtain a diversity of experience related to SSME programs. Inclusion criteria were being 18 years or older and diagnosed with diabetes for at least 12 months. The questionnaire, with a participant information sheet and a self-addressed envelope, was distributed to 550 patients by four nurses, one general practitioner, and the first author from December 2008 until March 2009.

### Instrument

For the survey, a questionnaire was developed by the authors to measure local awareness of SSMEs, assess the reasons for not attending the programs, and stages of change in readiness to attend the programs and to attain patient-rated self-efficacy scores. The question items were based on information derived from different sources including the literature review and discussions with experienced healthcare professionals working in diabetes care, as well as Leeds University staff responsible for teaching diabetes-related modules. The researcher also made contact with researchers from other disciplines (long-term conditions), who worked in the field of self-management research, to obtain various perspectives about the content of the questionnaire. Together, these sources produced a rich blend of perspectives which helped to identify and shape the domains and question items which were included in the questionnaire instrument. Several drafts of the questionnaire were developed, discussed with research team, and revised. The final questionnaire included an introduction outlining briefly the format of the questionnaire followed by eight sections including a mix of closed and open-ended questions. It included different sections including general and demographic information (10 questions) and the level of patients' awareness of SSMEs (4 questions). To explore the reasons for non-participation in the programs, 21 short statements were developed on a five-point scale from "Strongly agree," "Agree," "Don't have a view," "Disagree," to "Strongly disagree." These statements were developed by using the constructs of Health Belief Model<sup>[11]</sup> and Theory of Planned Behavior.<sup>[12]</sup> Furthermore, a validated self-efficacy was used which consisted of 15 items to indicate how confident respondents were in performing their self-management.<sup>[13]</sup> A question was also used according to the Transtheoretical Model of Change<sup>[14]</sup> to identify respondents' readiness to attend an SSME program. The questionnaire was subsequently piloted with 41 patients in a diabetes clinic and two general practices. The internal consistency reliability of the questionnaire was measured by calculating a Cronbach's alpha coefficient for the entire scale and a score of 0.91 was achieved.

Leeds Research Ethics Committee and the School of Healthcare Research Ethics in the University of Leeds approved this study (reference numbers: 08/H1307/69 and SHREC/RP/153).

### Statistical analysis

Quantitative data were analyzed using the Statistical Package for the Social Sciences version 16 (SPSS Inc., Chicago, IL, USA). Data were summarized using counts, percentages,

means, and standard deviations. Chi-square test was used to investigate differences between the variables. The threshold for statistical significance was  $P < 0.05$ .

## RESULTS

Four hundred out of 550 completed and returned the questionnaire (response rate 73%). Majority of the respondents were males (56%) and were married (61%). The mean age of respondents was 55 years. Most (84%) identified themselves as white British, and over a third of the respondents (37%) had type 1 diabetes; the remainder reported a diagnosis of type 2 diabetes. Duration of diabetes ranged from 1 to 48 years. One third (35%) reported that they did not have any formal qualification, but most (65%) had a formal qualification.

Most (85%) of the respondents reported that they had not heard about any of the SSMEs. Of those who knew about SSME programs (15%), they had different levels of awareness and a small number of them had attended a program including Expert Patient Programs (EPPs),<sup>[6]</sup> X-PERT,<sup>[4]</sup> DAFNE,<sup>[3]</sup> and DESMOND.<sup>[2]</sup> This shows that most respondents had not attended the SSMEs; an attendance rate of 4% is remarkably low. Respondents who had obtained information about the programs had received it from a range of sources, but predominantly through healthcare professionals. Further data analysis showed that respondents who had a formal educational qualification ( $\chi^2 = 15.59$ ; 3 df,  $P < 0.001$ ), were younger ( $\chi^2 = 9.39$ , 3 df,  $P = 0.02$ ), and had employment ( $\chi^2 = 3.33$ , 1 df,  $P = 0.04$ ) were more likely to have heard about the programs than the other groups.

The respondents who had heard about the SSMEs but had not attended were asked to identify their reasons for this decision. The results indicated that most of the respondents believed that their “diabetes was well-controlled” ( $n = 39$ , 64%) and they “knew enough about diabetes” ( $n = 37$ , 69%). More than one-third of the respondents also reported that their diabetes was “mild.” Respondents ( $n = 16$ , 46%) reported that they did not believe they were at risk of developing complications of diabetes. However, two-thirds of the respondents ( $n = 22$ , 69%) disagreed with the statement, “patients with diabetes do not need to attend education programs.” Respondents identified a range of barriers to their participation in SSMEs. The barriers most frequently cited were a lack of information about the programs, time, cost (travel and time off work), living too far away from where the program is held, physical disability, language problems, and difficulty in understanding the content of the programs.

The questionnaire also sought to measure respondents’ perceived self-efficacy. Respondents’ scores on the diabetes self-efficacy scale ranged from 27 to 75 with a mean score of 60.9 (SD 11.4). Overall, most participants reported fairly high levels of self-efficacy for diabetes self-management in undertaking diabetes self-management. Further analysis indicated that respondents had highest confidence in “taking medication,” “checking blood sugar,” and “examining feet for cuts,” and lowest confidence in items related to “diet” and “physical activity.” The results indicated that respondents from minority ethnic groups had lower self-efficacy versus British ( $\chi^2 = 15.53$ , 12 df,  $P < 0.01$ ). Furthermore, respondents who had educational qualifications ( $\chi^2 = 10.39$ , 4 df,  $P < 0.05$ ) and those who were married ( $\chi^2 = 9.84$ , 2 df,  $P < 0.007$ ) had a higher self-efficacy score than the other groups (no qualifications and single).

The results also showed that 364 respondents intended to attend the programs. Of these, 75% were in pre-contemplation stage, 21% in contemplation stage, and 4% in preparation stage. Respondents with lower self-efficacy ( $\chi^2 = 25.9$ , 2 df,  $P < 0.001$ ), those with formal educational qualifications ( $\chi^2 = 4.13$ ,  $P < 0.03$ ), and those from ethnic minorities ( $\chi^2 = 12.13$ , 1 df,  $P < 0.001$ ) were more likely to express an intention to participate in SSMEs than the other groups (people with high self-efficacy scores, no qualifications, and white British, respectively).

## DISCUSSION

The results of the survey provide information on the level of awareness of the respondents about SSMEs and the factors potentially influencing the participation or non-participation in the SSMEs. The findings reveal that most respondents were unaware of such programs. It is to be expected that by the time data collection for this study was conducted (2008/2009), most patients should have been informed about such programs because most of the programs had been incorporated into National Health System (NHS) practice from 2003. Accordingly, one of the more likely causes of the low level of awareness is that the programs are not being routinely offered to patients with diabetes through the NHS. However, many of the respondents who heard about the SSMEs as a result of participating in this survey did not wish to participate in them in the future ( $273/364 = 75\%$ ). So, simply knowing about their availability was not sufficient motivation in itself to promote attendance.

This study did indicate that awareness of the programs was greater among younger, educated, and employed respondents. There are plausible reasons why younger

patients are more likely to know about the programs. First, it has been recommended by the National Diabetes Audit that specific attention should be given to raising awareness in younger patients, as those who are younger (less than 40 years) face a greater lifetime risk of complications.<sup>[15]</sup> Furthermore, studies have indicated that younger patients have a greater desire to participate in education and health promotion programs.<sup>[16]</sup>

Conversely, older respondents had lower awareness about the SSMEs, which might be experienced as more challenging by older people. The present study also revealed that respondents with no formal educational qualifications were more likely to be less aware of the SSMEs than those who had educational qualifications; they also had a lower tendency to attend the programs in the future. Thus, it seems that this group needs to be given greater consideration by the healthcare system due to the contribution of these factors.

The respondents received their information about the programs mainly from practitioners working in primary care. Nurses in primary care now have more responsibility for monitoring, educating, and providing self-management support for patients.<sup>[17]</sup> Health professionals in this setting may have less time to give information about the SSMEs or they may not be faced with demands from patients to provide more information.

While using multiple information resources leads to a higher number of healthcare visits,<sup>[18]</sup> in this study, only a small number of patients (23%) who had heard about the programs (15% of all the respondents) found the relevant information from sources such as journals, posters, family, and the Internet. Furthermore, none of the respondents who were informed of the programs had attained their information from TV and radio.

Almost half (46%) of the patients who had already heard about the SSMEs but had not attended believed that they were unlikely to develop diabetes complication. Furthermore, they believed that they knew enough about diabetes and that their condition was well controlled. Some respondents felt they were not at risk of diabetes complications and perceived their diabetes as not a serious illness. A lack of perceived seriousness of diabetes among patients is consistent with other studies.<sup>[3,19,20]</sup> Lawton *et al.* believed that this may be a mechanism that patients use to deny their “diabetic identity.”<sup>[19]</sup> Patients may also think that diabetes is a potentially serious condition, without believing they are susceptible to diabetes complications.<sup>[21]</sup> However, a motivating factor for participation in the programs is the feeling among patients that their condition is deteriorating.<sup>[22]</sup>

Respondents from minority ethnic groups had lower self-efficacy compared to White patients. These people might have poorly controlled diabetes,<sup>[23]</sup> and the use of interventions to increase self-efficacy in this group of patients might be helpful.<sup>[23]</sup> Furthermore, respondents with lower self-efficacy scores had more intention to participate in the SSMEs, suggesting those who have low self-efficacy may be more willing to look for alternative sources of support.<sup>[24]</sup> The interest in SSMEs among ethnic minority patients with diabetes may indicate an unmet need for such services in this group as well.<sup>[25]</sup>

The study had some limitations that must be considered in interpreting the data. First of all, the sample was recruited from a convenience sample from a target population, which limits the generalizability of these findings to other cities in the UK. The second limitation was that completion of the questionnaire required a given level of literacy. A third limitation was that this study was based on patients’ self-reported recall of information regarding SSMEs. The last limitation was that only a small number of the respondents were already informed and participated in the programs.

In conclusion, for self-management intervention in patients with diabetes to be most effective, all patients should be informed about the programs, and those who could potentially benefit need to be offered participation in the programs.

## ACKNOWLEDGMENTS

This study was supported by a grant by Iranian Ministry of Health, Treatment, and Medical Education. The authors wish to acknowledge the NHS in Leeds and all patients who participated in the study.

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**How to cite this article:** Ashtarian H, Woolridge M, Cheater F, Firth J. Factors influencing attendance at structured self-management education programs for diabetes. *Iranian J Nursing Midwifery Res* 2012;17:480-84.

**Source of Support:** This study was supported by a grant by Iranian Ministry of Health, Treatment, and Medical Education.  
**Conflict of Interest:** None.