

Research paper

Using qualitative research methods to inform the development of a modified version of a patient education module for non-English speakers with type 2 diabetes: experience from an action research project in two South Asian populations in the UK

MA Stone
Job to come?

N Patel
Department of Health Sciences, University of Leicester, UK

H Daly
L Martin-Stacey
University Hospitals of Leicester NHS Trust, UK

S Amin
Leicestershire Dietetic and Nutrition Service, UK

M Carey
University Hospitals of Leicester NHS Trust, UK

K Khunti
Department of Health Sciences

MJ Davies
Department of Cardiovascular Sciences

University of Leicester, UK

On behalf of the Diabetes Education and Self Management for Ongoing and Newly Diagnosed (DESMOND) Collaborative

What is known on this subject

- Patient education can contribute to the effective management of people with chronic diseases.
- Developing effective methods of educating people from ethnic minority populations with type 2 diabetes is challenging.
- Few studies have reported the development and implementation of educational interventions for migrant South Asians with type 2 diabetes.

What this paper adds

- We have demonstrated the feasibility of modifying an existing educational programme for English speakers to meet the needs of ethnic minority populations.
- The use of an iterative approach, involving qualitative methods, worked well for identifying and testing the modifications needed.
- The impact of high rates of type 2 diabetes in some ethnic minority groups should be recognised in training people from these communities to facilitate diabetes education sessions.

ABSTRACT

Structured education has been recommended for all patients with type 2 diabetes. Provision of appropriate education should recognise diverse language and literacy needs. This project formed part of the process of developing the DESMOND (Diabetes Education and Self Management for Ongoing and Newly Diagnosed) programme. The aim was to investigate the training and use of lay educators and interpreters to provide DESMOND education for two South Asian populations in Leicester and Peterborough. This investigation formed part of an action research project involving an iterative, reflective process of development, piloting and evaluation. The process was informed by the use of qualitative research methods including collection and analysis of data from observation, focus groups and interviews.

Findings showed that the action research approach was considered useful in terms of facilitating the development process through identification of key issues and focused reflection. After an initial

two-day training programme, interpreters were competent to act as facilitators, but longer patient contact time and more personnel were needed for sessions delivered via interpretation. More-intensive training needs were indicated for lay educators. The trainees' learning experience was influenced by high levels of diabetes in themselves or their families. Pilot education sessions were well received and positively evaluated by patients.

These findings showed that the methodological approach adopted worked well and was considered to have added rigour to the process of developing a modified version of an existing education module. Careful consideration needs to be given to training needs and the comparative training and provision costs associated with using interpreters or lay educators.

Keywords: diabetes mellitus, ethnic groups, patient education

Introduction

The National Institute for Health and Clinical Excellence (NICE) has recommended that all patients with diabetes should be offered structured education (NICE, 2003). Patient empowerment through education and self-management has also been advocated in the *National Service Framework for Diabetes* (Department of Health, 2001). The Diabetes Education and Self Management for Ongoing and Newly Diagnosed (DESMOND) education programme aims to provide a structured approach to education for patients with type 2 diabetes (Craddock, 2005; Davies *et al*, 2008). The module for newly diagnosed people is based on a written curriculum, and delivered by trained and quality-assured educators over six hours as either a full-day or two half-day sessions. The philosophy underlying the DESMOND approach to patient education recognises the value of individual responsibility, and the curriculum aims to encourage and facilitate self-management. The content and format of the curriculum are underpinned by Leventhal's common sense theory (Leventhal, 1980), social learning theory (Bandura, 1977) and dual process theory (Chaiken, 1996). Patients with type 2 diabetes are managed mainly in primary care (Goyder *et al*, 1998; Khunti and Ganguli, 2000) and the initial DESMOND module for patients with a new diagnosis is currently being offered in an increasing number of UK primary

care trusts. A randomised controlled trial evaluating the English language version of the DESMOND module for newly diagnosed individuals has demonstrated a clinically useful but non-significant reduction in glycated haemoglobin levels and statistically significant improvements relating to weight loss, smoking cessation, self-reported physical activity, illness beliefs and depression (Davies *et al*, 2008).

Black and minority ethnic (BME) groups are strongly represented in the populations of many western countries including the UK. Census data for the UK for 2001 indicate that 7.9% of those included described themselves in ethnic categories other than white (www.statistics.gov.uk). The need to provide equitable and inclusive health care has been emphasised (Department of Health, 2003) and the importance of recognising cultural differences has been highlighted through research specifically related to providing services for patients with diabetes (Greenhalgh *et al*, 1998; Stone *et al*, 2005; Davies, 2006; Lawton *et al*, 2006). The DESMOND module for newly diagnosed people was initially developed for English speakers, but with a firm intention to subsequently consider the needs of patients from ethnically diverse communities. The identification of methods of modifying this module to provide fit-for-purpose education for BME patients has included a project based on action research methods (Stringer, 1999; Meyer, 2000), involving two South Asian communities in Leicester and Peterborough, and an African and Caribbean population in London.

The aims of this project included identification of key issues, problems and solutions, alongside consideration of the effectiveness of the action research approach involving the use of rigorous qualitative research methods. Cultural issues aside from language needs were considered, particularly in our work in London, where our study population was mainly English speaking (Stone *et al*, 2006). Language is one component of culture and the two issues are therefore interlinked; our work with Gujarati and Mirpuri-Punjabi speakers in Leicester and Peterborough, respectively has included consideration of issues such as health beliefs, cultural preferences and relevant foods. However, this paper focuses mainly on our experience of identifying and addressing methods of modifying diabetes education to meet the language needs of non-English speakers, with particular reference to South Asian populations.

DESMOND education is generally delivered to English speakers by health professionals: nurses, dieticians and doctors. However, a shortage of health professionals with relevant language skills meant that other strategies needed to be explored for our work in BME communities. We therefore report our experience of delivering DESMOND education with facilitation by interpreters or using lay educators without

health professional qualifications. An additional consideration involved meeting the needs of patients with limited literacy skills in their mother tongue.

Formal quantitative evaluation of the modified programme was not within the scope of the action research project, although the process of development involved piloting and qualitative evaluation. In this paper we report on the methodology developed and implemented for modifying the educational programme, and our assessment of its effectiveness; the modifications made to meet patients' language, literacy and cultural needs; and also qualitative feedback from piloting.

Methods

The project received ethics committee and local research governance approval. The action research approach in Leicester and Peterborough included partnership working between the academic research team and DESMOND trainers and educators. Our methods involved developing and testing strategies using an iterative process similar to the audit cycle. This methodology (see Figure 1) includes the use of data collection

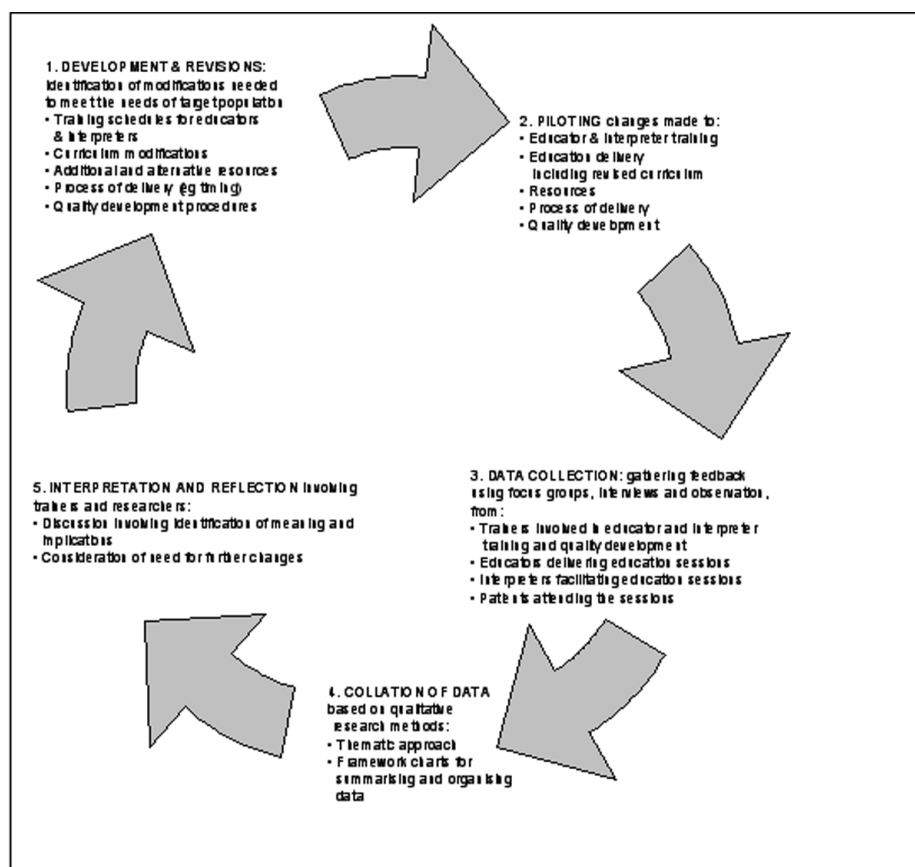


Figure 1 Cycle of revisions, piloting, feedback and reflection used in modifying a diabetes education programme

and analysis using rigorous qualitative research methods to gather and consider the implications of feedback from key stakeholders including healthcare users, providers and facilitators. Each cycle involves identification and implementation of modifications needed; piloting, including data collection using methods such as observation, interviews and focus groups; collation and analysis of data collected; and interpretation and reflection; followed by identification of further changes needed. The cycle is repeated until piloting suggests that a fit-for-purpose model has been developed.

Resources and curriculum format

Delivery of the standard DESMOND curriculum involves frequent use of writing on flip-charts to record patients' responses. A number of leaflet-style worksheets are also provided for patients to record information about their current health status and for goal setting and action planning. To address the potential problems of varied literacy skills, a series of images and pictorial leaflets was developed in collaboration with two illustrators. The development of the images involved consideration of the specific information or message that needed to be conveyed; relevance, irrespective of age, sex and ethnicity; cultural appropriateness; and clarity. The series included images depicting causes, symptoms and consequences of diabetes, for example being overweight, thirst and amputation, and images relating to behavioural change such as reducing portion size and being physically active. Identification of culturally relevant food models was specifically considered as part of the overall project (Stone *et al*, 2006), but as an interim measure for pilot sessions, some South Asian food models were provided by a specialist diabetes dietician involved in the project. In addition, it was recognised that interpretation would involve additional delivery time, and a longer format delivered over four sessions was therefore developed. Modifications made to the programme are summarised in Box 1.

Box 1 Summary of main adaptations made to the DESMOND newly diagnosed module to address language, literacy and cultural needs

- Development of a series of images to replace or supplement writing on flipcharts
- Development of pictorial versions of leaflet-style worksheets used during education sessions
- Identification and provision of culturally appropriate food models
- Development of a four-session version of the curriculum to address preference for shorter sessions and to provide time for interpretation

Training lay educators and interpreters

Nine interpreters were recruited through a process of advertisement, short-listing and interview. For the purpose of this study, lay educators were defined as people without a healthcare professional qualification; a total of 13 people were recruited opportunistically for this role. In Leicester these comprised five people involved in the Project Dil community initiative (Farooqi and Bhavsar, 2001) and two people working in healthcare support roles. In Peterborough, six lay educators were recruited from a range of community projects known to the local diabetes specialist nurse involved in the action research study. The original two-day educator training programme for healthcare professionals was modified by a team of DESMOND trainers and it was subsequently delivered to the trainee interpreters and lay educators recruited in Leicester. Prior to attending the course, trainees were provided with a pack of reading materials relating to diabetes. Qualitative data collection included semi-structured focus groups with the trainers and trainees, facilitated by experienced qualitative researchers involved in the project. These focus groups were based on flexible topic guides and they were audio-taped and transcribed. In addition, observational notes were recorded by the academic research team. The combined data were analysed using qualitative methods based on the framework approach. This involved familiarisation, development of a thematic framework, indexing and charting (Ritchie, 1994). Findings were used to guide a process of reflection to inform subsequent stages of the project (see Figure 1).

Patient education sessions

In Leicester, two sets of research-based DESMOND education sessions were run for Gujarati-speaking patient volunteers recruited by practice nurses at local general practices. A series of four sessions was delivered by two experienced DESMOND educators, with facilitation by interpreters who had attended the training sessions. The other course was delivered over two sessions during which some of the lay educator trainees delivered sections of the DESMOND curriculum in Gujarati. A series of semi-structured interviews with patients who attended the education sessions was conducted by a researcher with Gujarati language skills. Where permission was given, interviews were audio-taped but note taking was offered as an alternative. Informed consent to attend the research-based education sessions and for participation in interviews was obtained from patients. Notes and recordings from the interviews were transcribed in English, and framework methodology was used to analyse interview data together with observational notes collected during the

education sessions and feedback from the educators involved in delivering the sessions.

Additional development work

The first cycle of modifications, feedback and reflections was carried out for the action research project. Following this, a second cycle was undertaken in Leicester as part of the further development work of the DESMOND team. This included further piloting of the educational intervention with a group of patients and relatives recruited by the local secondary care diabetes care team. Training needs for educators and interpreters have been further developed and piloted as part of our current work aimed at providing education for people with a diagnosis of pre-diabetes, including people from BME communities.

Findings

Resources and curriculum format

Observation and feedback indicated that, overall, the pictorial resources worked well for making the education sessions accessible to patients with diverse language and literacy needs. Modifications suggested from the qualitative feedback were subsequently used in the further development of these resources. Suggestions also emerged for minor amendments to the four-session format for the curriculum, but overall this was found to be feasible and also acceptable to those delivering and receiving education.

Recruitment and training of lay educators and interpreters

Analysis of the qualitative data collected from the training programme in Leicester highlighted a key theme related to levels of learning and different roles. This theme can be used to illustrate the way in which our use of qualitative methods informed and facilitated the iterative approach adopted (see Figure 1). The modelled DESMOND sessions during the two-day training programme required trainees to role-play patients with diabetes. It appeared that they had often found it difficult to switch between their role-play persona during the modelling and their role as potential educators or interpreters during reflection sessions. It also appeared that the trainees had been learning about diabetes on a number of different levels. They were learning in relation to their roles as trainees preparing to work as educators and interpreters, but they were also learning to acquire knowledge about

the condition for themselves, in many cases as people with diabetes or with affected family members. They frequently related their learning to other work roles such as involvement in community projects. These factors appeared to inhibit focused learning directly related to delivery or facilitation of the DESMOND module.

Trainees' apparent concentration on acquiring knowledge about diabetes appeared to have restricted their ability to benefit from those aspects of the training programme designed to provide them with the skills related to delivering education, including the DESMOND patient-centred style of delivery. Trainees generally demonstrated a limited grasp of the concept of lesson planning and little awareness of the content and role of the curriculum folder provided. Both trainees and trainers acknowledged a need for both further training in diabetes knowledge and opportunities to practise delivery style and obtain feedback, in order to increase competency and confidence. In addition, those being trained expressed some anxieties stemming from the fact that they had not assimilated some of the information given relating to practicalities of delivering DESMOND. For example, they were not fully aware that educators work in pairs rather than alone; that a health professional educator would be available to provide support during sessions delivered by lay educators; and that all resources for the education session would be provided. Additional issues highlighted included concern about the difficulty of translating some words or concepts, particularly medical or technical terminology, where there may be no direct or obvious equivalent in South Asian languages. Examples cited included the words 'depression' and 'polyunsaturated'.

Key lessons learnt from reflecting on the data collected are summarised in Box 2. As part of the iterative and responsive process of developing an appropriate training package during the course of the action research project, some additional training in diabetes knowledge and a number of opportunities to practise delivery were organised in Leicester. The training programme delivered in Peterborough was revised to address some of the issues raised in Leicester, for example, the need to emphasise the role of the curriculum was addressed by including a quiz aimed at encouraging familiarisation with the folder provided. The revised programme also included a clear explanation of practical considerations relating to delivering the module, and greater emphasis on ensuring that trainees understood the concept of role-playing. There was also an opportunity for trainees to select, prepare and practise delivery of a small section of the module.

Box 2 Factors to be considered in training lay educators and interpreters to deliver and facilitate education sessions for non-English speakers with type 2 diabetes

- Formal rather than opportunistic recruitment may be preferable for ensuring a high standard of trainees.
- Higher levels of training are likely to be required for lay educators compared to interpreters to work alongside health professional educators.
- Delivery style and use of the curriculum need to be addressed specifically during training. Learning in these areas may not be absorbed when combined with providing knowledge about diabetes to trainees without a health-professional background.
- Trainers should be aware of the perspective of trainees who have diabetes themselves or in family members, and the way in which this may influence learning.
- It is important to ensure that practical expectations and quality-assurance procedures are clarified to prevent unnecessary anxiety.
- Opportunities to practise and obtain feedback are important for increasing competency and confidence in lay educators.
- Lay educators may initially need to concentrate on developing competency to deliver specific sections of the curriculum and build on this gradually.
- Guidance may be needed in terms of translating specific words and concepts for which there may be no direct equivalent in some languages.

Pilot education sessions

The pilot sessions held in Leicester as part of the action research project were attended by a total of ten patients and two relatives. Feedback from patients was generally very positive both in terms of knowledge gained and the interactive delivery and learning style, including the food games:

'It is a good way, very good way to gain knowledge.'
(Patient no 2, male)

'I did not know how much sugar is there. We could be drinking Pepsi or 7-Up or eating jelly or mithai [Asian sweet] and not know. From the games we got to know, from that we know not to eat a lot.'
(Patient no 5, female)

'Everything was fine . . . we got to know everything, how it [diabetes] happens and how to control all that.'
(Patient no 6, female)

In their accounts of changes they had made following the education sessions, it was clear that those who attended had assimilated some key messages from the education programme, for example the importance of quantity as well as quality in making food choices.

The English-speaking educators who delivered sessions with interpretation felt that this format worked well, and the patients who attended also indicated that they were happy to learn through an interpreter. In general it was considered that the training provided had equipped the interpreters adequately to act as facilitators. Lay educators demonstrated high levels of enthusiasm and made a useful contribution, but they had not obtained adequate competency levels to deliver the full curriculum. The two sessions originally planned for delivery in Gujarati were therefore run partly in English with interpretation. Feedback from patients who attended these sessions suggested an appreciation of delivery in their mother tongue, but it was clear that the lay educators needed considerable further training to enable them to deliver a full education programme.

Second cycle

Following the second cycle of implementing and evaluating modifications, it was agreed by the team involved that any minor additional changes needed to the curriculum and resources could be made without the need for further piloting.

Discussion

Escalating rates of type 2 diabetes throughout the world have been much publicised. There is an urgent need to find ways of limiting this rising prevalence, but it is also imperative to identify methods of improving biomedical and psychological outcomes in people with this condition. Research to date has been able to provide only limited evidence for the effectiveness of educational interventions for people with type 2 diabetes (Loveman *et al*, 2008), emphasising the difficulty of developing and implementing programmes that will lead to improved outcomes for patients. Specific barriers related to providing effective education for ethnic minority groups add an additional layer of difficulties in terms of achieving and evaluating effectiveness (Khunti *et al*, 2008). Nevertheless, the hypothesis that effective self-management education can improve patient outcome is based on sound principles, for example in relation to behaviour change, and there is a continued need to develop and rigorously evaluate programmes designed to meet the needs of a wide range of communities worldwide, including migrant populations.

Although the development of education programmes is often likely to involve an iterative process including piloting, reflection and revision, our action research project enabled us to add the rigour of qualitative research methods. Our methodology included a degree of objectivity by involving academic researchers in the process of data collection and analysis, and we were able to gather, analyse and consider the views of a range of stakeholder groups including patients, trainers, experienced healthcare professional educators and trainee interpreters and lay educators, together with data collected through observation. In collecting and analysing the data, we adopted a pragmatic stance, as often employed in health services research, in order to address the specific aims of our project in terms of evaluating and guiding the process of making modifications to the education programme. Nevertheless, the qualitative methods used were underpinned by the principles of grounded theory (Glaser, 1992) in terms of our awareness of the need for our findings to be grounded in, rather than imposed on, the data. In addition, our reflective approach to the analysis of the data enabled us to move beyond simple evaluation to consider the reasons why things had, or had not, worked optimally, for example in relation to training lay educators.

Facilitating education sessions using interpreters appeared to be an easy option in terms of training people to an adequate standard, but this approach has cost implications with regard to the need for additional people to run each session, and the extra time required for interpretation. However, these costs need to be balanced against the likely higher expense of training lay educators with appropriate language skills. It was felt that a more rigorous process of recruitment and a revised training programme based on the lessons learnt from the action research project could help to reduce the training time needed for lay educators. Nevertheless, training lay educators would still take longer than the time required to train interpreters. The challenging nature of training lay people as diabetes educators has also been reported in relation to training bilingual health advocates to work with South Asian patients in London (Greenhalgh *et al*, 2005). The training needs of lay educators and the effectiveness of using lay people to deliver DESMOND education for both standard and BME groups, are currently being further explored as part of a separate research project.

In some settings, people with diabetes can add personal experience to the process of supporting or educating patients and can contribute to motivation by acting as role models. However, we found that having the condition or affected relatives could create problems during training to facilitate or deliver DESMOND structured education. Trainees appeared to relate their learning about diabetes to their own experience and their own eagerness for knowledge.

This restricted their ability to view the knowledge being acquired, in terms of its application to the specific messages and delivery style of the DESMOND education programme. This observation is applicable more widely than within BME communities, but it is likely to be a particular consideration when recruiting lay educators and interpreters from ethnic groups such as South Asians, amongst whom the prevalence of diabetes is likely to be raised (Mather and Keen, 1985; Samanta *et al*, 1987). In common with all forms of education, lay educator and interpreter training therefore needs to be planned and conducted with an awareness of personal experience and learning needs, in this context specifically taking account of the influence of the high prevalence of diabetes in the community.

Overall it was felt by all involved that adopting the rigour of a research-based approach had contributed to the value of the project in terms of the useful lessons learnt. We ensured that the emerging format of the modified programme took account of the views of a range of stakeholders, and our analysis of the pooled data encouraged those involved to reflect on the reasons underlying problems encountered. Roll-out of the DESMOND module for South Asian patients newly diagnosed with type 2 diabetes has now been scheduled. The methodology developed is also being used to inform ongoing projects related to modifying and piloting education sessions for different groups of patients, and training schedules for educators and facilitators. In addition to further work relating to lay educators, as mentioned above, these projects include delivering education to people with pre-diabetes, including BME groups. During the development phase of this pre-diabetes project, the iterative approach and use of qualitative methodology was very positively evaluated by those involved, suggesting good transferability of our methodology for modifying education programmes in other settings. Identification of specific modifications needed to make the DESMOND newly diagnosed module appropriate for BME populations (see Box 1) has enabled us to develop both standard and BME versions of the pre-diabetes education module concurrently. A large-scale randomised controlled trial of the pre-diabetes programme is currently planned; this will allow us to formally evaluate the effectiveness of the programme, and the methodology used in its development, in ethnically diverse populations.

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ADDRESS FOR CORRESPONDENCE:

Dr Margaret Stone, Department of Health Sciences, University of Leicester, 22–28 Princess Road West, Leicester LE1 6TP. Tel: +44 (0)116 2523217; email: mas20@le.ac.uk

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