Making education in diabetes culturally appropriate for patients

ABSTRACT

Aims: The purpose of this study was to identify key cultural issues relevant to providing appropriate education for people newly diagnosed with type 2 diabetes in a UK African and Caribbean community. An additional aim was to test the usefulness of the collaborative action research approach used to gather this information.

Methods: An education and research event was organized in partnership with local diabetes educators and community groups in Southwark, London. This included a modelled education session and focus group feedback about cultural relevance based on a semi-structured topic guide. Qualitative methods were used to analyse the data collected.

Key findings: The action research approach and the topic guide used for the focus groups effectively identified relevant foods and other cultural issues such as traditional large portion sizes and social pressures related to food consumption in the African and Caribbean community. Language was regarded as the main barrier to joint education sessions for people from diverse ethnic backgrounds.

The main focus of managing patients with type 2 diabetes falls on primary health care providers (Goyder et al, 1998; Khunti and Ganguli, 2000). The importance of providing good quality education for patients with this condition has been emphasised (Department of Health, 2001). The aim of one patient education programme, the Diabetes Education and Self Management for the Ongoing and Newly Diagnosed (DESMOND) is to provide a structured and quality-assured approach which recognizes the importance of individual responsibility and encourages and facilitates patient self-management (Cradock, 2005). DESMOND education includes activities such as games and involves a high level of patient input for generating ideas. The full programme, which continues to undergo development, includes an initial module for newly diagnosed patients which is offered in almost 80 primary care trusts. It is delivered over 6 hours by trained educators including practice nurses and dietitians.

This DESMOND module for the newly diagnosed is being rigorously evaluated to assess its effectiveness in a multi-centre randomized controlled trial (Davies et al, 2005). Concurrently, consideration is being given to methods of modifying the content and delivery of the module to provide fit-for-purpose education for patients from black and minority ethnic populations.

Black and minority ethnic groups comprise sizeable proportions of the UK population: 7.9% of the population described themselves in categories other than white in the 2001 census (National Statistics, 2004). The importance of acknowledging cultural differences and needs has been recognized in the context of providing services for patients with diabetes (Greenhalgh et al, 1998; Stone et al, 2005; Lawton et al, 2006; Davies, 2006). Work to implement DESMOND for patients from black and minority ethnic populations has included an action research project involving Gujarati-speaking South Asian populations in Leicester, Mirpuri-Punjabi-speaking people in Peterborough and African and Caribbean patients in the Southwark area of London.

This article is a description and discussion of work in Southwark with the black and minority ethnic population which was mainly English speaking. The action research focused on issues aside from language with the aim to identify and explore issues which might be important in raising cultural awareness among educators working with patients of African and Caribbean origin.

Action research is a process that involves reflective practice and participant involvement (Stringer, 1999). The work in Southwark involved local DESMOND educators and community groups in the planning and conduct of the project, including recruitment of participants. In addition to identifying key cultural issues in the local community, the effectiveness of using rigorous qualitative research methods combined with features of action research to identify cultural needs was investigated.

Methods

This action research project was approved by Leicester Northamptonshire and Rutland Research Ethics Committee. Local research governance approval was obtained in London. An outline plan of investigation was reached through a joint 'brain-storming' meeting involving members of the University of Leicester academic research team and a group of local primary and secondary health-care providers and facilitators involved in diabetes care in London. It was decided to organize a combined education and feedback event at a community venue and additional involvement from patient participation groups and community organizations was subsequently enlisted. Participants were recruited by letter of invitation or using posters displayed by local community groups. Invitations stated that the event was open to local African and Caribbean people who either had diabetes themselves or had a family member with diabetes. There was also an option of bringing an accompanying person and lunch was provided. The full event was scheduled to last about 2½ hours, but it was made clear that volunteers could attend only the educational component if they wished.

The DESMOND newly diagnosed module is based on a structured curriculum from which a number of sections were selected for modelling during the first half of the session. This sampled education session was delivered by two experienced local DESMOND educators. The sections of the curriculum selected were 'the patient story' in which people are invited to share their experiences, plus a number of games in which patients explore the sugar, fat and omega-3 content of foods and also different types of fat.

The DESMOND curriculum gives guidance on the length of sessions, but there is likely to be some variation according to the number of patients in the group and levels of participation. Although the delivery style and key messages were retained in the curriculum extracts modelled, some concessions were made because of limited time available during the event. For example, the patient story was modelled using a small sample of volunteers rather than the full group who attended.

Following the modelled education, those who attended were invited to contribute to a discussion and feedback session. Volunteers were divided into two focus groups which were facilitated by members of the research team. The focus groups were based on a previously prepared topic guide, the development of which had been informed by earlier stages of the action research project and other previous work in patients from ethnic minority (South Asian) populations (Stone et al, 2005).

The purpose of the focus groups was to elicit the views and ideas of participants in relation to a number of specific considerations regarding the organization and content of DESMOND sessions for patients from black and minority ethnic communities. Particular emphasis was placed on identifying appropriate foods for the food games to ensure relevance and appropriateness for African and Caribbean people. Some of the topics for discussion differed between the two groups to ensure maximum coverage of issues within the time available.

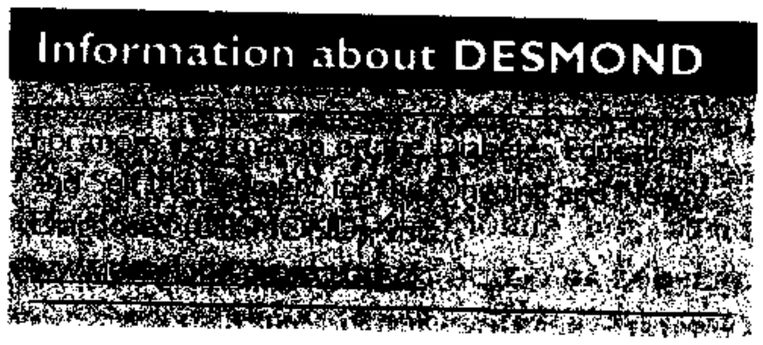
To facilitate discussion of appropriate foods, focus group participants were each given a set of lists of the food and drink items usually included in the DESMOND food games. They were asked to consider which if any of these might appropriately be excluded. They were also invited to make suggestions for any additional items that might be added to increase the cultural relevance of the games.

Other topics for discussion included practical considerations such as preferences in terms of length, timing and venues for education sessions and the potential need for separate sessions according to ethnic group and gender.

Information about health beliefs and cultural practices was also sought including types of physical activity undertaken. In addition, participants were invited to comment on the DESMOND style of education and the resources used.

A flexible, semi-structured approach was adopted and at the end of the sessions participants were invited to contribute any additional views or information which they felt might be relevant. The local DESMOND educators were also asked whether they had any additional issues which they wished to raise with the group.

All participants signed a consent form after being given a verbal explanation of the study



and the opportunity to ask questions or raise concerns. Informed consent included giving permission to tape record the focus groups, and notes were also taken by the facilitators. Transcriptions and summarized notes from the two focus groups were subsequently analysed thematically using the Framework approach (Ritchie and Spencer, 1994). Results were summarized and fed back to collaborators in the action research project; this included dissemination to focus group participants via the main recruitment source.

Results and discussion

Twelve people with diabetes plus one relative attended the education and research event. The best source for recruitment was a general practice patient participation group specifically for African and Caribbean patients with diabetes. All those who attended the education session agreed to stay and participate in the focus groups. Some key findings from the focus groups are summarized below.

Practical and organizational issues

It was confirmed by one of the groups that it would not be necessary to hold separate DESMOND education sessions for African and Caribbean patients because English is widely spoken in these communities. Participants did not believe that people from these two ethnic groups would need to be educated separately either from the white population or from each other. In addition, the group did not perceive a need to hold separate sessions for men and women.

Community centres were considered to be good venues. Although both focus groups preferred a format of two half days rather than one full day, one group also mentioned that this would depend on the individual and his/her commitments. One participant stated that making the sessions relevant to African and Caribbean communities would be more important than timing. He said:

> From what I have observed . . . if they are relevant to the people the timing is irrelevant.

Beliefs and practices

Health beliefs and associated practices were discussed by one of the groups and one participant raised the point that people from this community might look for answers to the question of why the prevalence of diabetes is higher in some ethnic groups:

> It's always written that it's most popular amongst Afro-Caribbean or Indian or some parts of Portuguese and all that. Why is that? Why is that we are more prone to having diabetes than say the white European?

This may be a question that educators working in this community would need to be prepared to discuss. When asked about the use of alternative treatments for diabetes that educators may need to be aware of, participants mentioned some treatments intended to improve general wellbeing which might also be used for diabetes. These included sera seed, noni juice (commonly used in Jamaica), Milagro de la Selva tea (used in some African communities) and glyco-nutrients.

Participants were asked about types of exercise typically undertaken and attitudes to exercise in their communities. Walking was suggested as the most common active behaviour. Attention was also drawn to the fact that a very sedentary life style was traditional for older people in their community:

> . . . actually not moving much, and it makes it with older people more difficult to manage their diabetes, 'cos what happens is even walking around it's sort of like too much of a problem.

Style of education and use of pictorial resources

Focus group participants were asked for their reactions to the DESMOND style of education as observed during the modelled sections of the curriculum. Feedback was very positive in relation to the non-didactic approach and there was a strong feeling that people from their community would respond well to this style of learning. As one participant said:

> Not sitting here and them telling you not to use this or do that. . . . It's all there and then you're seeing it, you see the practical side. . . . and that helps a lot.

Participants had found the messages easy to understand and felt that they would remember things because they were 'new and surprising'.

Participants in one of the groups were shown samples of a series of images developed for potential use in delivering the DESMOND newly diagnosed module to patients from black and minority ethnic com-

munities. Those in the group were asked for their views on using the pictures together with or instead of writing on flipcharts and whether this would assist with people's understanding of the education sessions. The group raised the issue of some people in the community having limited literacy skills and they therefore believed that pictorial resources would be very useful. It was also stated that, in general, a mixture of words and pictures would work well:

> Pictures would help because if you can't remember . . . you know, you look at the picture.

Other issues

Other issues raised by focus group participants included the need for more information and education about portion sizes. It was acknowledged that eating large portions could be a problem in their community. The need for advice on cooking methods was also mentioned, for example, steaming instead of frying and the impact of adding fat such as coconut milk to foods like rice and peas.

Participants also mentioned a cultural issue faced by patients with diabetes in social situations where they are likely to feel under pressure to eat certain foods, sometimes in large quantities:

> When we visit somebody the first thing on the table is food and you feel awful and a ton of pressure—it's an insult not to eat.

Relevant foods for food games

In general, the standard items included in the food games seemed to be acceptable, although participants identified a few items which were rarely or never eaten in their communities, e.g. ready-prepared fish paste. However, it was felt that it would be a good idea to include some 'local' foods to increase the relevance of the games. Some of the items suggested are listed in *Table 1*.

Conclusions

Focus group participants regarded language as the key factor that might set apart people from different ethnic groups. Because they were mainly English speaking, they therefore believed that they did not need to be educated separately from other English speakers.

Participants perceived that cultural differences were mainly related to food. Making education sessions more inclusively relevant could be achieved through raising educators' awareness of cultural issues. They could also be encouraged to increase cultural relevance during education sessions with ethnically diverse groups, for example, by including or referring to foods commonly consumed by each ethnic group.

In reflecting on the methodology used, it was considered that the education and research event had been very useful in terms of identifying locally relevant food items and other issues which could assist with raising cultural awareness in DESMOND educators working in African and Caribbean communities. The collaboration between the university researchers and local educators and community groups worked well in terms of planning and organizing the event and recruiting a useful sample of participants for the focus groups.

The use of qualitative research methodology facilitated appropriate use of the limited time available, using a topic guide based on previous research. The lists of the 'standard' foods included in the DESMOND games were very useful for stimulating and focusing relevant discussion and this format has subsequently been used to generate ideas about culturally appropriate foods in the two South Asian study populations in Leicester and Peterborough. Thematic analysis in line with qualitative research methods also helped to ensure that useful data were extracted from the content of the focus group discussions.

Overall it is believed that this action research approach and the qualitative methodology used had enabled the researchers to

Table 1. Examples of culturally relevant foods for diabetes education, suggested by African and Caribbean participants in two focus groups held in Southwark, London

Carbohydrates and sugary foods (for consideration of sugar content)	Swe…
	Plant…
	Cond…
	Hard… ead
	Mang… ago juice
	Carr…
	Coco…
Fish (for consideration of omega-3 content)	Salt fi…
	Red …
	Tilapi…
	Croak…
Types of fat (saturated, polyunsaturated or monounsaturated)	Cocon… oil
	Palm …
Additional items (for consideration of fat and calorie content)	Salt fi…
	Fried …
	Patti…

make a useful contribution to understanding the needs of patients from the black and minority ethnic community under consideration. The methods used are transferrable to other communities.

Acknowledgments

Margaret Stone and Naina Patel on behalf of the DESMOND BME group. The action research project was funded by Diabetes UK. The authors wish to acknowledge the help received from a range of individuals and organizations in Southwark, including those who contributed to the original planning meeting and those who assisted with recruitment. The authors also wish to thank the people who attended the education and research event and contributed to the focus group discussions.

References

Cradock S (2005) Structured education for type 2 diabetes patients. *Practice Nursing* 16(4): 176–9

Davies K (2006) Addressing the needs of an ethnic minority population. *Br J Nurs* 15(9): 516–9

Davies MJ, Heller S, Khunti K, Skinner TC on behalf of the DESMOND collaborative (2005) The DESMOND (Diabetes Education and Self Management for Ongoing and Newly Diagnosed) programme: From pilot phase to randomised controlled trial in a study of structured group education for people newly diagnosed with type 2 diabetes mellitus. *Diabet Med* 22(Suppl 2): 333

Department of Health (2001) *The National Service Framework for Diabetes: Standards*. The Stationery Office, London

Goyder EC, McNally PG, Drucquer M, Spiers N, Botha JL (1998) Shifting of care for diabetes from secondary to primary care, 1990-5: Review of general practices. *BMJ* 316: 1505–6

Greenhalgh T, Helman C, Chowdhuri AM (1998) Health beliefs and folk models of diabetes in British Bangladeshis: A qualitative study. *BMJ* 316: 978–83

Khunti K, Ganguli S (2000) Who looks after people with diabetes: primary or secondary care? *J R Soc Med* 93: 183–6

Lawton J, Ahmad N, Hanna L, Douglas M, Hallowell N (2006) Diabetes service provision: A qualitative study of the experiences and views of Pakistani and Indian patients with type 2 diabetes. *Diabet Med* 23: 1003–7

National Statistics (2004) Population size: 7.9% from a non-white ethnic group. 8 January. www.statistics.gov.uk/cci/nugget.asp?id=455 (accessed 22 November 2006)

Ritchie J, Spencer L (1994) Qualitative data analysis for applied policy research. In: Bryman A, Burgess R, eds. *Analysing Qualitatative Data*. Routledge, London: 173–94

Stone M, Pound E, Pancholi A, Farooqi A, Khunti K (2005) Empowering patients with diabetes: A qualitative primary care study focusing on South Asians in Leicester, UK. *Family Practice* 22: 647–52

Stringer ET (1999) *Action Research*. Sage Publications, London