

# Primary care



## Sharing stories: complex intervention for diabetes education in minority ethnic groups who do not speak English

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BMJ 2005;330:628-31

### Abstract

**Objective** To develop and refine a complex intervention for diabetes support and education in minority ethnic groups, delivered through bilingual health advocates.

**Design** Action research framework—a variety of methods used in an emergent and developmental manner, in partnership with clinicians, managers, and service users, drawing especially but not exclusively on narrative methods.

**Setting** Deprived inner London district.

**Interventions** Development and evaluation of three components of the complex intervention: a group based learning set for bilingual health advocates, in which stories about clients with diabetes formed the basis for action learning; advocate led support and education groups for people with diabetes, which used personal stories as the raw material for learning and action; organisational support to help to develop these new models and embed them within existing services.

**Results** Both advocate groups and user groups were popular and well evaluated. Through storytelling, advocates identified and met their own educational needs in relation to diabetes and the unmet needs of service users. In the advocate led user groups, story fragments were exchanged in a seemingly chaotic way that the research team initially found difficult to facilitate or follow. Stories were not so much told as enacted and were often centred on discussion of “what to do.” Whereas some organisations welcomed, successfully implemented, and sustained the advocate led groups, others failed to do so. A key component of the complex intervention was organisational support.

**Conclusions** An action research approach allowed engagement with an underserved group of health service staff and with hard to reach service users. The study produced subjective benefits to these groups locally as well as a worked-up complex intervention that will now be formally tested in a randomised controlled trial.

### Introduction

Ethnic differences in outcomes of diabetes are largely explained by differences in socioeconomic status, lifestyle choices (smoking, diet, exercise), and access to

services.<sup>1 2</sup> The most vulnerable groups are hard to target with lifestyle interventions, as they speak little English, are relatively isolated from mainstream society, and have variable knowledge of and motivation to use conventional health services.<sup>3</sup>

Empirical studies of education in self management of diabetes have been diverse in design, generally psychological in perspective (oriented towards individual beliefs, attitudes, and behaviour), and heterogeneous in impact.<sup>4-7</sup> We have taken a more anthropological perspective (studying the shared values and meaning systems that embed the individual behaviour choices of members of a cultural group).

In this study we aimed to develop informal storytelling as a complex intervention and evaluate its acceptability and subjective benefits to patients and staff. Our theoretical framework was action research, which focuses on change and improvement; involves a cyclical process of collecting, feeding back, and reflecting on data; explicitly and proactively involves participants (such as clinicians, managers, bilingual health advocates, and service users); looks reflectively at questions that arise from practice; and is educational for both researchers and participants.<sup>8 9</sup>

The four year study was based in two inner London boroughs and delivered through a local voluntary sector charity. Details of the community and setting have been published separately.<sup>10</sup>

### Methods

The action research cycle is described elsewhere.<sup>10</sup> The different phases were: mapping the extent of diabetes and services for diabetes in the locality; developing a learning set for bilingual health advocates; on-site work with the advocates; and setting up and sustaining diabetes groups led by the bilingual health advocates. Each phase of the study had different goals, used different methods, and was evaluated through different data sources (see [bmj.com](http://bmj.com)). In addition, an independent qualitative researcher conducted semistructured



Two extra tables and a summary of evidence on diabetes groups are on [bmj.com](http://bmj.com)



This is the abridged version; the full version is on [bmj.com](http://bmj.com)

interviews with all the research team one year into the project and again 18 months later. These interviews, and the focus group evaluations of the advocate groups and user groups, were audiotaped, transcribed, and analysed for themes by using the constant comparative method. We combined the different qualitative and quantitative data sources in each phase to build up a rich picture of the problem area and inform the design of the next phase of action.

## Results

We have presented the results as four overlapping phases corresponding to four “spirals” of the action research cycle. For each phase, we have highlighted the particular findings that fed into the design of the complex intervention (box).

### Phase 1: set-up

Background data sources showed that the study area had all the hallmarks of a deprived, under-resourced, multiethnic inner city area. Despite commendable efforts by some individuals and teams, vulnerable people with diabetes often received haphazard care. Community based diabetes nursing, dietetics, and chiropody posts were unfilled. Hospital clinics were overcrowded, and advocacy services were severely stretched. Very few primary care teams had special interest or training in diabetes. As a result, delayed diagnosis of diabetes and its complications was common.

The main lessons from this phase for the design of our complex intervention were that it must be closely embedded in workforce planning and human resource strategies and it should seek to create a large pool of appropriately trained individuals rather than relying on staff remaining in post for the duration of the study.

### Phase 2: training for bilingual health advocates

Our questionnaire data showed that the bilingual health advocates were a highly diverse group, with formal education varying from primary school to degree level. They dealt with huge numbers of clients with diabetes, yet few had had any training in diabetes and none had been formally trained in patient education. Most rated their own knowledge and confidence in dealing with diabetes as poor. Our qualitative data also revealed their deep commitment to their most needy and vulnerable clients; high personal workload; a strong tradition of didactic, instructional educational methods both in their own training and in their work with clients; lack of specific training for key aspects of their role; lack of protected time for reflection or discussion about difficult and stressful cases; and (in some) a profound feeling of professional isolation. Almost none had any experience in running groups, and all said that they would not be confident to do so.

The lesson from these data was that in addition to providing a sound training in basic diabetes knowledge, training for advocates must provide support, develop the individual, and consider the process of learning as well as content. For this reason, we refined the training into a supportive “learning set” format in which we modelled the principles of effective adult learning, group facilitation, and the storytelling (“case history”) approach to exploring service users’ needs.<sup>11–13</sup>

Attendance at the learning set was high (85% overall). We documented high levels of satisfaction with the course in general and the group storytelling approach in particular. We also showed an appreciable increase in self assessed knowledge and confidence in supporting clients with diabetes. We registered the 12 week course as a nationally accredited training option with the London Open College Network.

The first learning set was restricted to 13 female Bangladeshi advocates. In a subsequent course for a further 11 participants, we included Gujarati, Persian, Somali, Turkish, Arabic, and Chinese speakers of both sexes.

### Phase 3: bilingual health advocates in the work environment

Once trained and ready to apply group based storytelling techniques with clients, most advocates found they had neither the authority nor the resources to set up and run such groups. They and their managers needed considerable support to get a pilot advocate led group going. In some cases, there was palpable resistance from middle management to what was seen as a radical new service model (advocates leading patient groups rather than doctors using advocates in a reactive interpreting role). Because of the major challenges encountered in this phase, we added organisational support as a key component of the complex intervention (box).

#### The complex intervention

##### Component 1—Bilingual health advocate training

1. Initial three hour “taster” session for advocates to identify and reflect on their learning needs in relation to diabetes and group support. Run as structured but informal discussion. Refine learning objectives and a syllabus for definitive sessions
2. Definitive programme of 10 more formal, structured sessions, each on a different theme. Participants share stories about clients in small groups and then feed back selected “good stories” to a larger group facilitated to reflect on clients’ unmet needs and professional educational and support needs. Stories, not textbook “facts,” are used as the basis for learning. Each participant must write up one story as “homework” on a structured template (see [bmj.com](http://bmj.com))

##### Component 2—Organisational support for establishing advocate led groups

1. Engagement of top and middle management
2. Human resources support to modify job descriptions and lines of accountability (for example, to allow an advocate to telephone a diabetes specialist nurse without going through a manager)
3. Establish regular time and venue for group session and implement referral mechanism (such as self referral, referral by advocate, referral by doctor or nurse)
4. Engage clinicians to refer patients and support advocate led initiatives

##### Component 3—Running advocate led user groups

1. Advocate establishes supportive and informal atmosphere
2. Participants encouraged to form their own informal subgroups. Strong emphasis is placed on the telling of personal stories about diabetes and its impact
3. At an early session (though not necessarily the first), themes are suggested by group members for subsequent sessions. Examples of themes include drugs, exercise, shopping, feeling sad
4. Advocate organises appropriate health professional (if needed) to attend themed session “to answer the group’s questions.” At these joint sessions, advocate acts as interpreter and presents representative stories to the health professional, who is invited to respond (see [bmj.com](http://bmj.com))
5. Themed sessions should include action oriented activities (such as cooking, self monitoring, looking at shoes, trying out exercises)

### What is already known on this topic

Conventional diabetes education is often inaccessible to patients who do not speak English, and may be culturally inappropriate

Bangladeshi patients with diabetes attribute health related lifestyle changes to stories told by other Bangladeshis

### What this study adds

Diabetes support and education groups led by bilingual health advocates and using a "sharing stories" format are popular with staff and service users

"Learning set" style training based on stories about clients increases advocates' confidence and skill in running these groups

Organisational support is needed to implement this service model

#### Phase 4: developing and supporting advocate led user groups

Different advocate led user groups developed their own format and identity. We describe one example here. St Lucia's (pseudonym) is a community centre on a deprived estate in East London, attended mainly by elderly Bangladeshis. A regular women's lunch club had been established, and the attenders, despite having lived in the United Kingdom for 20-30 years, spoke little English. Many were strict Purdah observers and wore a burqa covering all but the eyes. A straw poll at one of the lunches had shown that around half of the women had known diabetes and most had a first degree relative with the condition. A weekly "diabetes storytelling group" was established by word of mouth and proved popular from the outset. It grew from eight to 42 regular attenders in 18 months and developed in ways we did not anticipate. Participants were not willing to sit in a circle, taking turns telling stories, nor were they willing to be organised or facilitated by the research team (AC and NB attended all meetings, with NB acting as interpreter; TG attended around one meeting in four). They used us mainly as a resource, to answer questions about medical issues or diet, or to comment on a story. Much of the discussion took the form of animated arguments between participants about some or other aspect of diabetes, which we were often called in to resolve. To a visitor, the group would have seemed chaotic, with multiple conversations occurring at once and women wandering about the room, coming and going as they pleased, and often bringing friends or grandchildren with them.

The advocate led groups were "doing" groups rather than "talking" groups. For example, many women attended to check their blood glucose concentrations on our meter, even though we had provided them with their own. Interestingly, whereas the biomedical model implies that people will compare their blood glucose result with their own previous results, these women compared their own glucose level with other people's levels, a process that led to reflection within the group, with comments such as "she didn't have a second helping and look, her result is better than yours."

Overall, the group's mean glucose concentrations did not change, as new attenders were often poorly controlled (many were sent to the group by local primary care staff who were concerned about their

poor control). Glucose concentration in longstanding attenders decreased over time, but the change did not reach statistical significance. A focus group evaluation (undertaken a year after the group began) was very positive. A representative comment was, "If someone has diabetes and doesn't know what to do, they should come to the group first, and they will learn what to do."

Whereas several other advocate led groups failed to become mainstream for reasons set out in the previous section, the St Lucia's group, as well as one other group, has continued with core NHS funding (both, incidentally, with diabetes specialist nurse support). The lesson from this phase for the complex intervention is that story based group intervention for minority ethnic groups may look and feel very different from traditional diabetes group education.

## Discussion

Action research is a feasible way of developing complex interventions involving combinations of service redesign, professional development, and user education. Complex interventions need an extensive development phase to optimise the components, implement delivery (including staff training), and develop model explanations of mechanism before being tested in randomised controlled trials.<sup>14</sup>

Although the bilingual health advocate led diabetes support group is a simple and appealing concept, we have shown that setting up such groups involves at least three separate components. Only when all this has been achieved can a definitive trial of the efficacy of the intervention be started.

Because the user groups are driven by individuals' stories and fuelled by their actions, each group will be different. This accords with contemporary thinking that whereas the core principles of a complex intervention should be clearly set out, considerable scope should be allowed for varying the operational detail as teams on the ground adapt the intervention to local needs and circumstances.<sup>15</sup>

A theoretical limitation of user groups led by non-clinicians is the danger that incorrect and even dangerous clinical advice might be shared in the group. We did not encounter any such examples. Most discussion focused on standard diabetes education topics (diagnosis, diet, exercise, check ups) and comprised making sense of complex situations and exchanging "how to" advice (cook brown rice, swim in long dresses, and so on). The groups proved surprisingly skilled at identifying areas in which advice from clinicians was needed and sought this readily. Nevertheless, this potential limitation should be a focus of inquiry in the next phase of the research.

Our qualitative findings suggest that the mechanism by which group participation might achieve positive outcomes is not principally through acquisition of knowledge but by providing a forum in which participants can negotiate the meaning of knowledge and by prompting action. Although it is often assumed that education occurs by the transmission of knowledge from an educator to learners,<sup>4</sup> the reality in both the advocate learning set and the user groups was that knowledge was repeatedly discussed, reframed, and challenged by the group, and only then made meaningful for the participants. Denning (among oth-

ers) has written of the powerful link between storytelling in group situations and subsequent action by individual participants.<sup>16</sup> Because of the detailed analysis of what actually went on in the groups, this study has contributed considerably to the research literature on group based education in diabetes (summarised on [bmj.com](http://bmj.com)).

This study has provided unique insights into the feasibility of setting up diabetes support and education groups for both bilingual health advocates and service users and into the process of learning, empowerment, and change in such groups. The impact of the intervention should now be tested in a randomised controlled trial.

We thank the service users, bilingual health advocates, and many other stakeholders who participated so enthusiastically in setting up and evaluating the groups described here. Their names are listed in the "Sharing stories" workbook. We especially thank John Eversley, Jill Russell, Anita Berlin, and Farida Malik for conceptual and practical input at different stages.

Contributors: See [bmj.com](http://bmj.com)

Funding: The study was funded by Diabetes UK.

Competing interests: None declared.

Ethical approval: The local research ethics committee approved the study.

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## Commentary: Using patients' narratives in complex research

Ross E G Upshur

The use of narratives is attracting attention in health care as a means of exploring and sharing experiences of health, interactions with the health care system, and as a research method, in and of itself. How narratives function as part of a complex research programme is a less explored terrain. Greenhalgh and colleagues are to be commended for their innovative and novel approach to creating an intervention for diabetes education with the specific aim of engaging bilingual health advocates to facilitate narrative or story telling approaches as a part of a programme to improve diabetes management for a vulnerable and neglected population.<sup>1</sup>

The study is itself part of a story. Like an early chapter in a book, what we see before us is only an indication of what is to come, and as with all good stories it clarifies some dimensions of the plot but leaves others untold. Greenhalgh and colleagues clearly show the difficulties and describe the barriers required to get an action oriented research programme functioning, and they are candid in both their successes and failures. It seems that a user group led by a bilingual health advocate can be successfully implemented in some circumstances, but not in all. Considerable effort is required to ensure the acceptability and sustainability of the programme.

I wonder whether the authors have explored the possible harms associated with this type of research. One of the important findings was that participants did not compare their blood glucose results to previous results, but compared their results to each other's: "She didn't have a second helping and, look, her result is better than yours." Considerable trust and support is

required for this kind of disclosure and public discussion of a personal narrative in a public or group setting. I hope that victim blaming didn't have an important role and that surveillance, patrolling, and intrusiveness did not become a part of the lives of the people who shared information about their diabetes. An example would be a social occasion when people say "You can't eat that, you're diabetic." The ethical demands of action research are relevant but are rarely discussed.

The story of this study is not yet completed. This report will leave readers anxious for the next installment. Greenhalgh and colleagues have established the feasibility of establishing diabetes support and education groups with bilingual health advocates and service users, revealing novel insights. They now propose a randomised control trial. Will they engage their study communities in the creation of this randomised trial, particularly seeking input from the group on the desired outcome measures and the magnitude of effect expected by such an intervention? The importance placed on outcomes by different participants in the research process varies greatly. Narrative approaches are ideally suited to capturing this diversity and I hope that, true to the researchers' methods, the community has as much input in the conception of the randomised trial as it has had into the development of this important study.

Competing interests: None declared.

1 Greenhalgh T, Collard A, Begum N. Sharing stories of complex intervention for diabetes education in minority ethnic groups who do not speak English. *BMJ* 2005;330:628-31.



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