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Primary care

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

Trisha Greenhalgh, Anna Collard, Noorjahan Begum

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.^{1,2} 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.³

Empirical studies of education in self management of diabetes have been diverse in design, generally psychological in perspective (that is, oriented towards individual beliefs, attitudes,

and behaviour), and heterogeneous in impact.⁴⁻⁷ Our own team has taken a more anthropological perspective (studying the shared values and meaning systems that embed the individual behaviour choices of members of a cultural group). Our previous research showed that positive behaviour changes (such as giving up smoking) in British Bangladeshis are almost always attributed by them to a story told in an informal setting by another Bangladeshi.^{8,9} 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) in the research process; looks reflectively at questions that arise from practice; and is educational for both researchers and participants.^{10,11}

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.¹²

Methods

The action research cycle, described in detail elsewhere,¹² is in some ways similar to the audit cycle, in that data are systematically and successively collected in order to evaluate progress towards a series of planned changes. The different phases of this study had different goals, used different methods, and were evaluated through different data sources, as summarised in table 1. In addition, we asked an independent qualitative researcher to conduct semistructured 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 method¹³; further details of the analysis are available on request. 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.¹⁴ For each phase, we have highlighted the particular findings that fed into the design of the complex intervention (box 1).



Two extra tables and a summary of evidence on diabetes groups are on bmj.com

Primary care

Table 1 Phases of the study and data collected

Phase	Goals	Main actions	Data sources
1 Set-up	Map the extent of diabetes and level of diabetes care in the locality; develop partnerships with key stakeholders; link our own work to existing healthcare and community development initiatives	Collect statistics on burden of disease and nature and extent of services for diabetes (NHS and voluntary sector); interviews with 35 people representing 13 organisations (hospitals, general practices, interpreting organisations, voluntary sector ethnic health groups)	Publicly available epidemiological data (for example, from local health improvement plan); published details of local services (such as information supplied to general practitioners); field notes from visits to stakeholder organisations; interview notes
2 Learning set for BHAs	Train a cohort of BHAs in the principles of diabetes care and in running support and education groups for clients with diabetes	Assess the background and experience of BHAs and their perceived training needs and learning styles; run two "taster" education sessions for BHAs, using interactive exercises with "Post-it" notes to identify and classify learning needs; develop and deliver a curriculum in a format appropriate to these needs	Semistructured (qualitative) interviews with seven NHS managers and two voluntary sector advocacy services; self completion questionnaire sent to 21 BHAs to assess knowledge, experience, and perceived learning needs (before and after the training course) (18 returned); participant observation in "taster" group sessions; Post-it notes and flipchart paper from these sessions; focus group evaluation of learning set led by independent qualitative researcher
3 On-site work with BHAs	Support BHAs to pilot diabetes groups for clients in their workplace	Work at organisational level to tackle human resource problems for BHAs (job description, level of autonomy, lines of accountability); support BHAs, their managers, and the wider organisation in establishing pilot groups and embed them in services	Ethnographic field notes from organisational visits; interviews with advocacy services managers; interviews with other diabetes staff (consultants, specialist nurses)
4 Diabetes groups for service users	Set up and sustain BHA led education and support groups for diabetes service users	Support BHAs in recruiting participants to groups, running the groups, engaging other health professionals in providing educational input, and evaluating the groups	Quantitative data on attendance, random blood glucose levels (measured by finger prick testing during the group); qualitative data: participant observation of all sessions plus one focus group of attenders during routine lunchtime session, led by NB; tape recorded, translated, and transcribed with consent

BHA=bilingual health advocates.

Phase 1: set-up

The background data sources in table 1 showed that the study area had all the hallmarks of a deprived, under-resourced, multi-ethnic 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, although one or two practices provided an exemplary service. As a result, delayed diagnosis of diabetes and its complications was common. At least five different organisations provided advocacy and interpreting services to the public sector. All were understaffed, and they communicated little with one another; most perceived themselves to be in a state of crisis.

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 named 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 (including link workers and voluntary sector interpreters) 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 of them 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 for the complex intervention was that in addition to providing a sound training in basic diabetes

knowledge, training for advocates must provide support, develop the individual (self esteem, motivation, and professional identity), and consider the process of learning (how it happens) as well as content (what is learnt).¹⁷ 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.¹⁸⁻²⁰

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. In liaison with a local community education and training organisation ("Making Training Work"), we registered the 12 week course as a nationally accredited training option with the London Open College Network ("Storytelling for group learning in health and care"). We wrote a trainers' workbook, which includes a detailed syllabus, formal learning objectives (reproduced in table A on bmj.com), and a template for participants to use when writing up their stories.¹⁶

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

After the training course, most advocates were confident in the principles of diabetes care and keen to apply group based storytelling techniques with clients. But most of them held low status positions in complex multiprofessional hierarchies and had neither the authority nor the resources to set up and run such groups. They and their managers needed considerable support (most crucially, buy-in had to be negotiated with top management and the medical and nursing hierarchies) to get a pilot advocate led group going. The difficulties were often logistical (for example, an advocate might not be allowed to telephone a nurse without going through a manager). 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 1).

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 burqua 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 antici-

pate. 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 (often about an encounter with a health professional). Much of the discussion took the form of animated arguments between participants about some or other aspect of diabetes, which we were often

Box 1: 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. Use small group flipchart and "Post-it" exercises to establish a list of potential topics and the level of interest and confidence in each topic. Refine learning objectives and a syllabus for definitive sessions
2. Definitive programme of 10 more formal, structured three hour sessions, each on a different theme. Participants share stories about clients in small groups (of three or four) and then feed back selected "good stories" to a larger group facilitated to reflect on clients' unmet needs and professional educational and support needs.¹⁵ Stories, not textbook "facts," are used as the basis for learning. Each participant must write up one story as "homework" on a structured template, as shown in box 2

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. Advocate ensures that the focus of discussion is on "explaining why X happened in the story" rather than "giving a talk on X." (See box 3)
5. Themed sessions should include action oriented activities (such as cooking, self monitoring, looking at shoes, trying out exercises)

Box 2: Example of a client's story written up by a bilingual health advocate (from a themed session on "diabetes in the family")

The story of Mrs Uddin

Mrs Uddin is a 35 year old Bengali woman. She is 20 weeks pregnant and already has three children. Mrs Uddin recently came to this country and was diagnosed with diabetes. She had to face many difficulties. She was missing her family in Bangladesh. Her husband works outside London and visits twice a week. She therefore stays with her in-laws. Mrs Uddin was expecting her husband to take her to the GP. She was feeling very tired. When she eventually saw the midwife she found out she was diabetic. She had to start taking insulin for which she was dependent on others. Her grandmother and father had also been diabetic. Her father had not taken care of his health and he died at the age of 50.

Learning she was insulin dependent was frightening for Mrs Uddin and caused her to become depressed. She did not understand why she had to take insulin and thought it might cause her to die like her father. Due to language barriers that existed, Mrs Uddin found it difficult to get the necessary help when she needed it. She relied on her sister-in-law to inject her with insulin, but she often had to wait long lengths of time for her medication as her sister-in-law was busy. Mrs Uddin had been to the hospital a few times. The linkworker and health advocate had been regularly monitoring her progress and feeding back the information to the health professionals.

Why did you choose this story?

Because of the many difficulties Mrs Uddin had to face being diagnosed with diabetes away from home.

What questions or issues does this story raise?

Through the advocates Mrs Uddin realised that not taking her insulin properly would result in detrimental effects on her unborn baby.

What are the learning points?

Mrs Uddin became much more responsible for her own health and had more help from her extended family once they had gained knowledge about the condition and how to treat it. Mrs Uddin did not previously understand diabetes and found it difficult to treat herself. After being advised by the linkworker and health advocate, Mrs Uddin realised the seriousness of her condition and sorted out taking her medication regularly.

Tutor's feedback to the learning group about this story

This story illustrates a number of issues common in a family with diabetes. Firstly, there is a positive family history and a "horror story" of a relative with early death. Secondly, the family members with previous experience of caring for diabetes are not the ones who are around when a new case is diagnosed (in this case, because they are back in Bangladesh). Thirdly, contrary to the popular stereotype, the support from this Asian extended family is inadequate—those who are competent to help also have their own lives to lead. Finally, there is a strong suggestion of both guilt and despair in the diabetic member: she is dependent on her relatives but also conscious of being a burden to them.

Reproduced with permission from the 'Sharing Stories' workbook¹⁶

Primary care

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.

One important finding from our observation at St Lucia's and other advocate led groups was the strong action orientation (the groups were "doing" groups rather than "talking" groups). For example, many women attended St Lucia's to check their blood glucose concentrations on our meter, even though we had provided them with their own meters and shown them how to use them. Interestingly, whereas the biomedical, individual care 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."

Another example of story enactment was when women brought outpatient appointment letters or leaflets and passed them around the group. Comments were provided in the form of advice on "what to do." One woman, whom we thought had been formally diagnosed as having diabetes and who had shown very high blood glucose concentrations on our meter, disclosed that her general practitioner had told her that she was "not diabetic," despite her taking him copies of our readings. The other women in the group followed the story of her repeated visits and became a source of indignant affirmation that the woman should persist in demanding a referral to a specialist.

Overall, the group's mean glucose concentrations did not change, as new attenders were often poorly controlled (indeed, 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 described here, as well as one other group based in a community hospital setting, has continued with core NHS funding (both, incidentally, with diabetes specialist nurse support). The longer term sustainability of these groups remains unknown.

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. Resistance exists to formal facilitation and to a pre-set agenda. Stories are often fragmented and may be enacted rather than told. The shared social event of reacting to the story and discussing different interpretations and possible endings can lead to both reflective learning and empowerment to take action. A key outcome of the group in the eyes of the participants was "knowing what to do about diabetes."

Discussion

This study has shown that 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.²¹ Progressively changing the focus of activity in response to participants' needs and priorities is an inherent feature of the action research design and allows continual refinement of the intervention as the study unfolds.¹¹ This leads to both immediate benefits for research participants and an "optimised" intervention suitable for testing in clinical trials.

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. Considerable effort must be put into training the advocates who will run the groups, providing practical support and specialist educational input to fledgling user groups, and supporting organisations to adapt existing structures, roles, and relationships to the requirements of the new service model. 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 (in this case, engaging the organisation, developing the advocate as an independent professional, using personal stories as a vehicle for learning, keeping the groups informal but structured, avoiding didactic teaching, and providing hands-on learning tasks) 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 (for example, when and how to approach key clinicians and managers, whether one or two advocates should be present in each user group, whether people can self refer to the group, and whether they can bring partners or friends).²² Depending on the qualifications, experience, and

Box 3: Example of an advocate led diabetes group session

Sorting out our drugs

A bilingual health advocate led Gujarati group based in a community hospital diabetes centre identified confusion about drug treatment as a major problem. The advocate invited a general practitioner with a special interest in diabetes to attend the group. The group members emphasised that they wanted help with their own particular drug (and drug combinations), not a talk on drugs in general. Everyone brought their tablets, insulin, or both along to the session.

The general practitioner was warned by the advocate before the session not to "give a talk." The participants sat in a circle, each with her drugs in a large carrier bag (which powerfully showed how many drugs they were all taking). They took it in turns to hold up a particular "problem drug" and describe the difficulties they had with it. Such tales drew further stories from the others in the group (for example, about gastrointestinal problems with metformin). Much enactment and laughter took place. Group members felt confident to tell the doctor through the advocate that they often did not take the drugs. Facilitated by the advocate, the doctor explained possible strategies for dealing with side effects of drugs, including titration of the dose against home blood glucose measurements, building up slowly to the recommended dose, tolerating the side effect, or arranging an interpreted consultation with their own doctor to negotiate a change in drug. The advocate made it clear throughout that the clinical management of individual members was not part of the group session.

The information gained from the group participants in this session led to the redesign of patient information leaflets about drugs for diabetes.

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

confidence of the advocate leading the group, different levels of support will be needed from a clinician (such as a diabetes specialist nurse).

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 in the groups we studied. Most discussion focused on standard diabetes education topics (diagnosis, diet, exercise, check ups) and comprised making sense of complex situations (see example in box 3) 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 (although this is clearly important) 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,⁴ 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. As Friere put it, "Knowledge emerges only through invention and reinvention, through the restless, impatient, continuing, hopeful inquiry men pursue in the world, with the world, and with each other."²³ Denning (among others) has written of the powerful link between storytelling in group situations and subsequent action by individual participants.²⁴ 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).

In conclusion, 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: TG and AC had the idea for the study and developed it in partnership with the multiple stakeholders referred to in the text. All authors shared the fieldwork. NB translated and transcribed tape recorded evaluation sessions. TG wrote the paper.

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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.¹

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.

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