The sharing stories model of diabetes self management education for minority ethnic groups: a pilot randomised controlled trial

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This study owes its success to the enthusiasm, commitment and hard work of many different individuals and groups. These include:

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- The group participants, whose personal efforts to educate and support others with diabetes were greatly valued. As one person put it, "After 35 years with diabetes I had begun not to care any more; the group has motivated me to care again".

The Report

1 Background

1.1 Introduction

Storytelling has attracted interest among diabetes educators as a potentially effective element of culturally tailored education (Greenhalgh, Collard, & Begum 2005b;Utz et al. 2008;Willging, Helitzer, & Thompson 2006).

The involvement of the patient in his or her own care is a popular theme in chronic disease management. Lay led 'expert patient' programmes oriented to increasing self-efficacy are widely encouraged (Donaldson 2003). But recruitment to such programmes from lower socio-economic and minority ethnic groups tends to be poor outside the research setting (Greenhalgh 2009), and recent systematic reviews have highlighted the mismatch between policy enthusiasm and the evidence base (Foster et al. 2007;Newbould, Taylor, & Bury 2006;Warsi et al. 2004). Group education in diabetes, when intensively delivered, culturally tailored, and closely linked to clinical care, improves long-term outcomes (Hawthorne et al. 2008;Loveman, Frampton, & Clegg 2008b;Trento et al. 2004). But again, attendance is typically low outside the research setting, especially amongst 'hard to reach' patients such as limited English speakers and those with low health literacy. Lay-led, community based peer support sessions for minority ethnic groups are popular and well attended in USA but have not yet been evaluated in adequately powered randomised trials (Feathers et al. 2007;Utz, Williams, Jones, Hinton, Alexander, Yan, Moore, Blankenship, Steeves, & Oliver 2008).

'Self management' is a contested term – referring variously to possessing a biomedical knowledge base and skill set, living and coping with illness in the social world, participating in illness-related networks and social movements, and critically addressing issues such as access to services or disability rights.(Greenhalgh 2009;Rogers 2009) Self management education programmes typically make people feel better but have little impact on clinical outcomes.(Chodosh et al. 2005;Newman, Steed, & Mulligan 2004) They are usually directed mainly or exclusively to biomedical goals (focusing, for example, on a structured curriculum of knowledge and skills) – a fact which some authors believe explains their limited success in people for whom self management is highly constrained by social and economic factors.(Newbould, Taylor, & Bury 2006)

1.2 Complex interventions

A complex intervention is one with more than one component, each of which is essential to the outcome (Campbell et al. 2000). The Medical Research Council recommends an extensive development period to achieve a robust, theory-based mechanism of action (phase 1), optimise the coordination and delivery of components (phase 2), and test these in exploratory trials (phase 3) before undertaking a definitive randomised trial (phase 4) (Craig et al. 2008). This study focused on phase 3 of this sequence.

Complex interventions often have an organisational component – requiring, for example, staff to be trained in new roles, patients to be referred to different individuals or departments or in different ways, or establishing new communication systems. But intervention research is usually led by clinicians, and organisational components are often weakly developed. This study sought to pilot a complex intervention in diabetes care, focussing on the organisational component and drawing on the evidence base for embedding service-level innovations in organisations. A systematic review by our own team found that the implementation and sustainability of organisational innovations depends on the fit between the innovation and the wider system and on the 'reinvention' of the innovation at local level to improve this fit (Greenhalgh et al. 2004). This aligns strongly with the recommendation that 'standardisation' of complex interventions for testing across multiple sites should be at the level of theoretical mechanism, not that of detailed protocol (Hawe, Shiell, & Riley 2004). In other words, local centres should be encouraged to customise complex interventions to fit local needs and priorities, so long as they retain the critical features of the mechanism of action.

1.3 Our previous work on bilingual health advocate (BHA)-led groups in diabetes

We have previously demonstrated that south Asians with diabetes attribute lifestyle changes (giving up smoking, changing diet etc) to the impact of stories told by other members of their community (Chowdhury, Helman, & Greenhalgh 2000;Greenhalgh, Helman, & Chowdhury 1998). In a four-year action research study of BHA-led group support for south Asians with diabetes, we developed and evaluated a complex intervention to promote group-based storytelling (and hence support behaviour change) in this group (Greenhalgh, Chowdhury, & Wood 2005a;Greenhalgh, Chowdhury, & Wood 2005b;Greenhalgh 2002;Greenhalgh & Collard 2003;Greenhalgh, Collard, & Begum 2005a;Greenhalgh, Collard, & Begum 2005b). Key findings from this phase of the research were:

- Bilingual health advocates (BHAs) working in diabetes care in multi-ethnic inner city settings have a high workload, an ambiguous and challenging professional role, and little formal training. They are often

at the front line of clinical scenarios which they feel ill-equipped and ill-supported to deal with;

- A 'learning set' style professional education and support group for BHAs, based on stories (case examples told orally in informal small groups) of clients with diabetes, led to dramatic increases in self-reported diabetes knowledge and confidence;

- BHAs trained in this way were keen to set up and run support groups for their clients, but establishing the groups required a fundamental change to the interprofessional power relations in the organisations where they worked. In particular, it was organisationally complex and critically dependent on support from top management, middle management, and health professionals;

- BHA-led diabetes story-sharing groups were popular, well attended, and characterised by vigorous discussion. Personal stories drove a collective search for further information, and individuals were encouraged by their peers to take action (e.g. give up smoking, go to their GP, overcome needle phobia).

- Random glucose levels measured during the sessions showed a trend towards reduction over time, but changes did not reach statistical significance. Qualitative evaluation suggested that members linked the group with improved ability to take practical action in relation to lifestyle and accessing services. A typical comment was "diabetic people should come to this group to find out what to do".

During this extensive action research phase, we developed strong links with local services. One or two organisations managed to sustain BHA-led diabetes groups on mainstream NHS funding; others raised short-term charitable or voluntary-sector funds. But whilst the groups continued, we still did not know if they were having any real impact on the health and well being of people with diabetes (as opposed to just being a popular social event), and questions remained about how best to support BHA-led groups at an organisational level. Hence, we sought to measure the impact of BHA-led story-sharing groups on clinical and psychological outcomes in an RCT design.

1.4 Aims and objectives of the study

The aims of the study were:

1. To measure the impact of BHA-led diabetes story-sharing groups for minority ethnic groups with diabetes on clinical, biochemical and psychosocial outcomes.

2. To collect and analyse the stories shared by participants, so as to illuminate the experience of diabetes and refine the intervention.

3. To explore process aspects of the intervention, especially the mechanism by which the group experience leads (or fails to lead) to improved outcomes.

4. To document and develop the organisational component, especially the patient pathway, human resource issues, data/informatics issues, costs, and sustainability.

The objectives of the study were to determine the following:

1. Baseline and follow-up data on a representative sample of participants in both intervention and control groups in terms of biochemical (e.g. cholesterol, HbA1c), physiological (e.g. body mass index) and psychometric (e.g. well-being, enablement) changes. These data would be used directly to quantify the impact of the intervention and also indirectly (if preliminary results were positive) to inform the sample size calculation for a definitive multi-centre RCT.

2. A richer understanding of the experience of diabetes in minority ethnic groups living in socio-economically deprived areas in UK.

3. Operational details on all tasks, processes and costs, especially those around the organisational embedding of the intervention – that is, what needs to be done by whom, and what systems need to be in place, to make this service model happen and become part of business as usual.

4. Final versions of necessary supporting materials for this intervention (for example, job descriptions, information protocols, data collection forms, training packs and resources, and so on).

5. Details of recruitment challenges and response rates at three levels: (a) recruiting and engaging individuals and teams in different parts of the system to participate in the study, (b) recruiting the BHAs to the training course, and (c) recruiting participants with diabetes to join the groups.

6. Quantitative information on group attendance, and qualitative information on the social processes occurring during the group sessions.

7. Unanticipated and indirect effects of this intervention on diabetes and other services.

2 Method

2.1 Management and governance

The trial was registered prospectively with the UK National Research Register, ISRCTN68516177. A project steering group with representation from community and lay participants as well as clinicians, local government and external academics met six-monthly. A research management group met three-monthly.

Ethical approval was gained from East London and City Research Ethics Committee (05/Q0604/142). Participants gave written informed consent for the trial and also for the collection and anonymised use of qualitative data in research. In the quotes below, we have deliberately withheld potentially identifying details such as age, gender and (in some cases) ethnicity. To provide additional protection, we selectively applied the critical fiction technique – that is, we systematically altered certain details so as to disguise the narrator and context (Winter 1986). A draft of this paper was shown to BHAs and to representatives of local patient groups before submission.

2.2 Participants and setting

The study was based in Newham, a socio-economically deprived inner London borough with a population of 260,000, 67% of whom are from minority ethnic groups. Diabetes prevalence is 4-6 times age-standardised UK means (local unpublished data). Using the UKPDS cardiovascular risk score (Stevens et al. 2001) we found that the five-year risk of cardiovascular death across the Newham diabetes clinic population was 28% compared to 16-24% in a typical age-matched UK diabetic population. Newham Diabetes Centre provides a consultant-led interdisciplinary service that spans primary and secondary care and has strong academic, community and voluntary sector links. Most diabetes education for both primary and secondary care patients is coordinated through the Centre, though some general practices offer additional educational input locally

2.3 Description of study

2.3.1 Study design

Randomised controlled trial with in-depth process evaluation. The study protocol is shown in Figure 1 overleaf. The complex intervention can be thought of comprising three separate components:

1. Training and support of the BHAs and lay volunteers who ran the story-sharing groups

2. The story-sharing groups themselves

3. Organisational support aimed at embedding the intervention in the work of the local diabetes service

Figure 1. Summary of study protocol
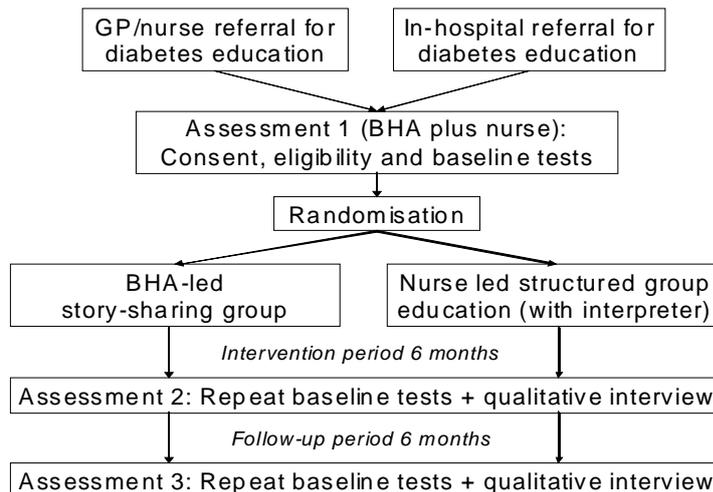
Allocation to intervention or control arm was concealed from both participant and researcher until the individual had been entered into the trial. Allocation to intervention or control arm was by permuted block randomisation (Doig & Simpson 2005). Concealment of allocation was maintained for all tests and analyses.

The sample size calculation was based on an estimated mean overall risk score of 24% in the control group at the end of the 12 months follow-up. Assuming a common standard deviation of 11.5% the total required sample size in order for the study to have 90% power to detect as significant at the 5% (2-sided) level a 6% difference in the 12 months mean overall cardiovascular risk score between intervention and control groups was estimated to be 160 (80 per group). In anticipation of one-third of those approached choosing not to join, the study aimed to target 240 people.

In one ethnic group (African Caribbean), small numbers meant that the group would have been too small, so three additional participants with

diabetes were recruited from outside the trial (by word of mouth). These individuals joined in the group and their stories and qualitative evaluation may be represented in this report, but they were not included in the quantitative analysis.

2.3.2 Inclusion and exclusion criteria

All patients referred to the Diabetes Centre for diabetes education by a standard referral form were considered potentially eligible and contacted by the research nurse assisted by a BHA. Those who expressed interest in the study were considered for randomisation. Most people with diabetes from minority ethnic groups in Newham have insulin resistance; most people randomised, including the 25% on insulin therefore had type 2 diabetes. Groups were offered in Bengali (Sylheti), Gujarati, Tamil, Somali, Punjabi, Urdu, and English (for African Caribbeans).

Patients were excluded if they were unable to speak one of the above languages fluently, unable to give informed consent, or judged by the referring clinician to be unsuitable for group education. Co-morbidity was not an exclusion criterion and those with mobility needs were offered minicab transport, allowing 'housebound' patients the opportunity to join the study.

2.3.3 Training and support of the BHAs and lay facilitators

The training, described in detail in the 'Sharing stories' training manual (Greenhalgh & Collard 2003) is an established course accredited by the London Open College Network. An initial three-hour 'taster' session allows BHAs to identify and reflect on their learning needs in relation to diabetes and group facilitation using stories about clients. Their stories are used as the basis for designing the detailed learning objectives and syllabus for 10 definitive group sessions spaced at approximately weekly intervals, delivered and overseen by a team that includes nurses, a diabetes-trained GP, an educationist or training manager, an equality and diversity manager, and specialist clinical input (e.g. consultant diabetologist, podiatrist) as needed. In the BHA groups, participants share stories about clients in small groups and use these in facilitated learning to identify clients' unmet needs and professional educational and support needs.

While the story-sharing groups were running, it was initially planned to provide a 'learning set' once a month for the BHAs and lay facilitators. In practice this proved impossible despite a budget for releasing the BHAs from their clinical duties, because of problems with back-fill of clinics.

2.3.4 The experimental intervention: sharing stories

Because our early research had identified informal stories (such as gossip or hearsay) told by an equal-status peer (as opposed to 'standardised' or 'expert' accounts) as the trigger for behaviour change (Greenhalgh, Helman, & Chowdhury 1998), so the intervention was intentionally unstructured and informal, and didactic teaching by staff was strongly discouraged.

Following Hawe et al, we recognised that complex interventions may include flexibility in application in different settings but must include a set of well-defined core components.(Hawe, Shiell, & Riley 2004) The core components of the sharing stories intervention were that:

- Sessions must involve spontaneous, informal and unstructured story-sharing (participants should be encouraged to tell whatever stories they want about their condition, in whatever order, with no stipulation of what is 'important' or 'legitimate');

- Sessions must be facilitated non-directively by a non-clinical professional or volunteer trained in the sharing stories model;

- Input of clinical professionals (doctors, nurses, dieticians etc) must be in the form of a response to the stories shared by group participants.

In practice, the groups were run as follows. Groups were organised in a venue judged suitable and acceptable by the BHA (mostly in a community venue but sometimes in a room on Trust premises). Each group had 6-12 participants; sessions lasted around two hours (but the venue was booked for three hours as many participants arrived late so a 'social time' was accommodated at the beginning); they were held two-weekly for 6 months.

Participants were encouraged to identify a theme for a forthcoming session, which was typically a topic that had emerged in discussion the previous session (e.g. 'feeding the family', 'medication', 'dealing with doctors'). They were asked to bring personal stories on the agreed topic next time, and also asked whether they would like a health professional (dietician, exercise specialist, diabetes nurse, etc) to come and respond to their stories. Pragmatically, some sessions were not as spontaneous as this – e.g. many professionals had to be booked weeks in advance – but the principle of participant-led, story-based topic discussions was followed as far as possible.

On arrival, participants had 10-15 minutes (sometimes more) 'social time' before being asked to get into 'buzz groups' of 2-3 and share their stories. After about 20 minutes, the facilitator invited them to regroup in a plenary format and asks "does any group have a good story to share?". This often allowed a story with important learning points to emerge, after being 'tried out' in the safety of the buzz group. Informal discussion on this story was encouraged, with a focus on the practicalities and moral challenges that the story raised. Whilst the generic design for the group session was around the 'told story', in practice many stories were enacted with visual 'props' –

for example pills are often passed round when discussing medication; or samples of rice when discussing glycaemic index. If stories prompted action (e.g. stories about exercise prompted the group to try out chair-based or stretching exercises), this was encouraged.

Thus, each story-sharing group was led by a BHA with some input from a clinician – most usually a diabetes specialist nurse but depending on the chosen session topic, a chiropodist, dietician, GP, pharmacist or physical trainer was invited to attend either as well as, or instead of, the nurse. The BHA facilitated the group in a non-directive manner, encouraging the sharing of personal stories about diabetes and its impact, which s/he interpreted and invited the health professional to comment on. The BHA sought to work actively with the health professional to ensure that the focus of discussion was on "explaining why X happened in the story" rather than "giving a talk on X".

2.3.5 The control intervention: standard group education

Participants randomised to the control group were invited to the standard group education sessions provided at Newham, comprising nurse-led structured educational sessions held either in the hospital or in the community. Trial participants were offered interpreter input at these sessions.

Some participants in both intervention and control groups also sought educational input from their GP or practice nurse; a small proportion were referred to the intensive DESMOND education sessions as this was introduced part-way through the trial (Davies et al. 2008). We considered it unethical to bar participants from taking up this opportunity. DESMOND consists of a total of six hours' structured input delivered by an accredited trainer and covering a pre-specified curriculum. As it turned out, fewer than 5% of the participants in this trial were referred to DESMOND and even fewer attended.

2.3.6 Outcome measures

The primary outcome measure was the UKPDS coronary risk score (a composite of blood pressure, smoking status, lipid ratio, atrial fibrillation, and HbA1c which has high predictive value in diabetes (Stevens, Kothari, Adler, & Stratton 2001)).

We used UKPDS in favour of HbA1c because the latter is a poor predictor of outcome in type 2 diabetes in the presence of cardiovascular risk factors (Duckworth et al. 2009). We chose the UKPDS because most morbidity in the target population was cardiovascular, and because UKPDS was the only diabetes-specific risk score validated for use in people of Asian and African ethnicity (R Holman, personal communication). Further details of the UKPDS risk score (including a downloadable risk score calculator and

examples of its use) are available from the UKPDS website http://www.dtu.ox.ac.uk/index.html?maindoc=/ukpds/

Secondary outcome measures defined in the original protocol were attendance, HbA1c, diabetes-related well-being (using a validated four-item scale designed for low-literacy minority ethnic groups with diabetes (Greenhalgh, Chowdhury, & Wood 2005b)), the Patient Enablement Instrument (a six-item questionnaire reproduced in Figure 2 (Howie et al. 1998)), and carbon monoxide breath testing for smoking status. In the event only a tiny fraction of the participants (6%) smoked so the last of these measures was not used.

Figure 2. Patient enablement instrument

As a result of participating in the story-sharing [or education sessions], do you feel you are:

1. Able to cope with life? (much better / better / same or less / not applicable)

2. Able to understand your illness? (much better / better / same or less / not applicable)

3. Able to cope with your illness? (much better / better / same or less / not applicable)

4. Able to keep yourself healthy? (much better / better / same or less / not applicable)

5. Confident about your health? (much more / more / same or less / not applicable)

6. Able to help yourself? (much more / more / same or less / not applicable)

2.3.7 Organisational support

The organisational support component aimed to integrate the trial seamlessly with the business-as-usual of a busy acute hospital trust and inter-organisational diabetes service. To that end, we undertook the following:

- Ensuring representation from the service and voluntary sectors on the project steering group.

- Ensuring that the progress of the study was regularly reported within the relevant leadership and governance structures, including the Modernisation Board (which was jointly chaired by the Chief Executives of both the acute and primary care trusts).

- Disseminating news of the project via talks at various seminars and meetings (e.g. GP postgraduate lunches, dieticians' study days, Trust research days) and via articles in internal newsletters.

- Integrating the referral and randomisation process with the standard triage that was already in place for all new referrals to the diabetes service.

- Ensuring that the research nurse and BHAs were welcomed as part of the diabetes multidisciplinary team.

2.3.8 Collecting stories

In order to capture the stories shared in the groups, we used a technique called naturalistic story-gathering – that is, collecting naturally-occurring talk during real social interaction (as opposed to asking people to give an interview in a controlled setting).(Greenhalgh, Russell, & Swinglehurst 2005) An anthropologist (APC) and a clinician (TG) attended a total of 65 story-sharing group sessions. We made ethnographic field notes on general group dynamics, issues discussed, emotions displayed and actions observed, which we typed up as soon as possible afterwards. These notes included only a small proportion of the stories shared, since to be captured, stories had to be translated by the BHA without interrupting the group discussion or spontaneously retold in English by a group member. In practice, some groups communicated in a combination of English and an ethnic language, especially when a researcher or other visitor (e.g. medical student) was present. Stories shared in the English-speaking (African Caribbean) group were captured directly. The strengths and limitations of this approach are considered in the discussion.

2.3.9 Process evaluation

The data sources for the process evaluation are summarised in Table 1.

Table 1. Data sources for process evaluation

Component	Quantitative process data	Qualitative process data
1. BHA training groups	Attendance rates, pass rates in formal course assessment	Ethnographic field notes; focus group evaluation
2. BHA-led patient groups	Attendance rates at sharing stories group or control group. Reason for exclusion	Ethnographic field notes; focus group with BHAs; reflection session with group participants
3. Organisational support	All formal documentation produced in relation to the study (job descriptions, task lists, protocols, minutes of meetings, etc). Informal documentation including emails, memos etc. Interviews with a representative sample of 13 organisational stakeholders (clinicians, top and middle managers, BHA managers, administrative staff, referring GPs). Whole team reflection session.	

In the last group session, participants were asked three qualitative questions:

1. What would you tell a friend with diabetes about this story-sharing group?

2. Did you change anything as a result of attending, and if so, what?

3. What should we change about the group?

Their responses, which were translated by the BHAs if necessary, were written down verbatim and transcribed. All transcripts were subsequently coded and analysed thematically with reference to various theories of learning, change and identity rebuilding in chronic illness (see Discussion).

The process evaluation of the organisational component was led by an academic in healthcare management (FBM) who otherwise had no input to the study. He observed meetings between researchers and NHS staff when discussing how to align the story-sharing model with mainstream services. He conducted a total of 13 semi-structured interviews (5 researchers, 4 clinicians, 4 managers) across primary and secondary care throughout the study period. A focus group with BHAs was also held, though clinical pressures reduced attendance to three participants. In addition, a two-hour whole-team review meeting, attended by 3 researchers, 3 clinicians, 7 managers and 7 BHAs, was held halfway through the study period.

Organisational interviews were guided by the following question list:

1. What did you think of the sharing stories project?

2. What do you think patients got out of it?

3. Do you think there were disadvantages or problems for any patients? If so, what were these?

4. How do you think the sharing stories model worked for the staff?

5. What were the challenges?

6. Assuming the impact on patients is positive, do you think this model of care could work as a mainstream NHS service?

    a. If so, what do you think would be the advantages?

    b. If not, why not?

    c. What would be the issues around commissioning this model of care?

7. If you were going to change the sharing stories model to make it better, how would you change it?

8. Do you think it would be feasible to do this as a multi-centre randomised controlled trial? Why?

9. What other questions do you think we should be asking you about this project?

2.3.10 Data management and analysis

We knew from the outset that this complex study would generate a large amount of data of different types (e.g. clinical measures, biochemical tests, questionnaire responses, field notes, semi-structured interviews, and contemporaneous materials such as minutes of meetings). A small data management subgroup (TG, DC-R, ACollard, MG) worked mainly by email to consider and address the collection, management, storage and analysis of data.

All quantitative data was entered anonymously on to a database using Epi-Data. All data were double entered and crosschecked for data entry errors. Identified errors were corrected with reference to the manual data collection forms. The clean data was imported to STATA version 9 for quantitative analysis.

We designed manual data collection forms to extract quantitative data from patient records, and developed a computer database on Epi-Info appropriate to the nature of the data. All data were anonymised in keeping with the Data Protection Act before putting on computer. Manual files, including anonymisation codes, were held under lock and key in accordance with standard data handling procedures at Newham University Trust and UCL; further details of these can be supplied on request.

MG undertook analysis of quantitative data. The primary analysis was a comparison of the UKPDS risk score between the intervention and control groups. This was undertaken for two time points: immediately after the end of the group work and after a further six months follow-up. Outcome measures were analysed using analysis of co-variance (ANCOVA) in order to compare differences in means between intervention and control groups, whilst adjusting for potential differences in baseline measures for that particular outcome. These comparisons were summarised as adjusted difference in means with their associated 95% confidence intervals and p-values from the ANCOVA. The analysis also assessed the impact of the intervention on predefined secondary end points as detailed above. Where baseline measures were recorded ANCOVA was used.

The unpaired t-test was used for the Patient Enablement Instrument, since this was only administered once, immediately after the end of the intervention period (because, as Figure 2 shows, it was designed to measure immediate reflections on an experience using the format as a result of the experience you have just had, how much better or worse do you feel?). Data were analysed on an intention to treat basis (i.e. individuals were analysed by the allocated study arm whether or not they actually attended the sessions). The Patient Enablement Instrument score for those who failed to attend any sessions was recorded as missing.

For qualitative data on the process aspects of the study, individual interviews were audio-taped and transcribed; for group discussions, researchers made contemporaneous notes and typed them up

immediately afterwards. Process data were coded, analysed thematically and synthesised using a multi-level model of how complex innovations are introduced and embedded in healthcare organisations (Greenhalgh, Robert, Macfarlane, Bate, & Kyriakidou 2004).

The stories shared in the groups were considered as a separate dataset. Stories can be considered in two ways: as qualitative data and as literature. We used both these approaches. First, we used the framework method to cut and paste sections of the data into a spreadsheet, develop and apply a coding system, and then combine codes into broader thematic categories (Ritchie & Lewis 2003). We drew on an existing knowledge base (the recommended 'evidence based' topic areas for diabetes self management education (Funnell et al. 2009;Khunti et al. 2008)) to develop a preliminary taxonomy, and amended this iteratively as the analysis progressed. In this initial stage we used the stories as a source of data fragments for content analysis, thus taking an essentially deconstructive approach (Donovan & Sanders 2005).

In a second stage, we took an explicitly constructive approach which considered the story as a whole as the unit of analysis. We studied the story for literary features such as genre (e.g. tragedy, comedy, epic), temporality (e.g. why a particular 'beginning', 'middle' and 'end' were assigned), characters (e.g. who was depicted as hero or villain; who was central or peripheral), context (how the stage or setting was described), and plot (e.g. how illness was depicted as 'trouble' that breaches the traditional practices and routines of everyday life) (Bruner 1990). In addition, we applied Bakhtin's dialogical approach and Reissman's notion of storytelling as performance to consider how the story was shaped by characteristics of the narrator, the listeners and the particular context in which it was being shared (Bakhtin 1981;Riessman 2008).

In interpreting the stories in this dataset, we drew particularly on two established sociological approaches to illness narrative: Anselm Strauss's theory of illness as biography (in particular the notion that coping with a chronic illness requires biographical work) (Strauss 1975), and Mishler's widely-cited paper on the two discourses which compete dialectically in clinical encounters: the Voice of Medicine and the Voice of the Lifeworld (Mishler 1984).

2.3.11 User involvement

The original plan was to set up a User Review Group of 'graduates' from our story-sharing groups, who would meet regularly to review the study protocol, consider emerging findings, feed into the project steering group, and assist with dissemination.

Whilst keen service users were identified, they were not keen to attend a regular, formal group and preferred to give feedback informally to trusted BHAs who in turn fed back these views to the project team.

3 Results

3.1 Demographics, follow-up and attendance

The baseline characteristics of the groups are shown in Table 2 below.

Table 2. Baseline characteristics of groups

	Intervention (n = 79)	Control (n = 78)	Total (n = 157)
Age in years (mean [SD])	60 (11)	56 (12)	58 (12)
Number of males (n [%])	21 (27 %)	26 (33%)	47 (30%)
Duration of diabetes in years (mean [SD])	7.0 (5.7)	5.9 (3.8)	6.4 (4.9)
Main language spoken (n [%])			
English (African Caribbean)	3 (4%)	4 (5%)	7 (4%)
Bengali / Sylheti*	23 (29%)	23 (29%)	46 (29%)
Tamil	11 (14%)	12 (15%)	23 (15%)
Urdu / Punjabi**	34 (44%)	32 (41%)	66 (42%)
Somali	7 (9%)	8 (10%)	15 (10%)
Diabetes treatment (n [%])			
Diet alone	4 (5%)	7 (9%)	11 (7%)
Oral hypoglycaemic agents	70 (89%)	64 (82%)	134 (85%)
Insulin (with or without tablets)	20 (25%)	19 (24%)	39 (25%)
Clinical findings (mean [SD])			
Body mass index in Kg /m2	29 (4.1)	30 (5.5)	29 (4.8)
Systolic blood pressure in mm Hg	133 (14)	135 (15)	134 (14)
Biochemical values (mean [SD])			
HbA1c %	8.2 (1.5)	8.2 (1.8)	8.2 (1.6)
Total cholesterol in mmol/L	4.2 (1.1)	4.6 (1.2)	4.4 (1.2)
Total cholesterol / HDL	3.9 (1.1)	4.1 (1.2)	4.0 (1.2)
Creatinine level in µmol/L	84 (25)	80 (19)	82 (22)
Current smoker	6	3	9
UKPDS 10-year risk score %			
Coronary heart disease	13.9 (9.9)	12.1 (9.6)	13.0 (9.8)
Stroke	8.0 (7.2)	6.0 (7.4)	7.0 (7.4)
Total	21.9 (16.4)	18.1 (15.8)	20.0 (16.2)
Diabetes well-being score***	13 (4)	13 (5)	13 (5)

* Sylheti is a dialect of Bengali.

** Punjabi / Urdu speakers attended a single group as there is much crossover between these languages; the facilitators and many participants spoke both fluently

*** where score ranges from 4 (lowest level of well-being) to 20 (highest)

The follow-up data are summarised in Figure 3.

Figure 3. Flow chart to show recruitment and follow-up
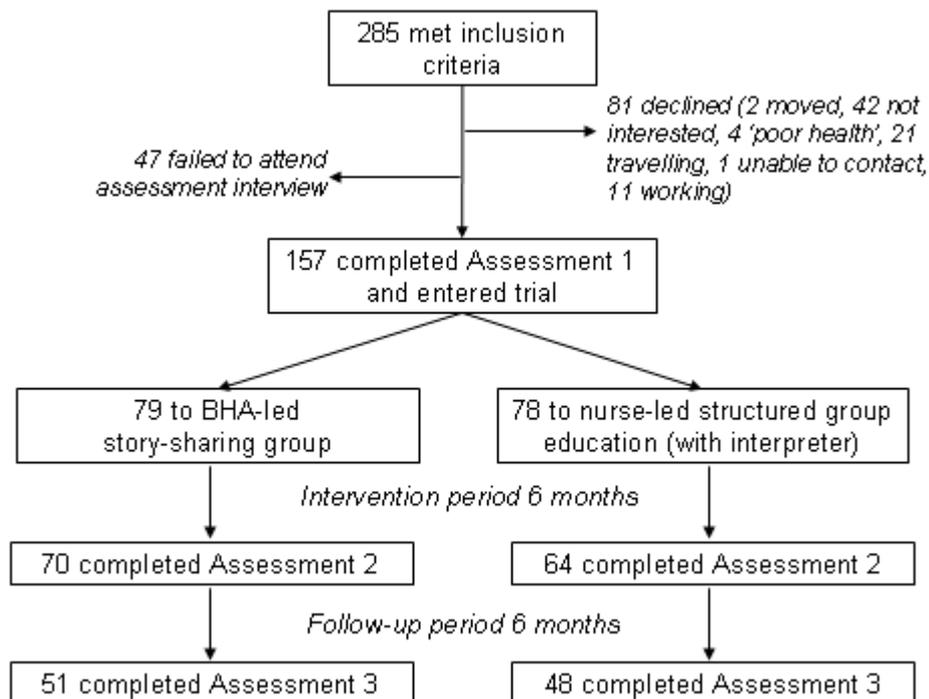
In all, 87% of participants were followed up at least once. The high follow-up was achieved by a research nurse and BHA visiting non-attenders in their homes to complete psychometric questionnaires, clinical examination and blood tests.

85% of participants randomised to story-sharing groups attended at least one such group; 35% of those randomised to standard nurse-led education attended at least one group. Many of the latter said that they had received diabetes education from their GP or practice nurse but had not wanted to attend any additional group education.

3.2 Quantitative findings

The results of the quantitative analysis are shown in Table 3.

There was no significant change in the primary outcome measure (UKPDS risk score) in either intervention or control groups. Secondary outcome measures were also unchanged with one exception. There was a highly significant difference in the Patient Enablement Score between intervention and control groups, suggesting that as a result of the story-sharing intervention, participants felt significantly better able to understand and cope with their illness and keep themselves healthy.

Table 3. Results of quantitative analysis of outcomes over time

ANCOVA analysis of data collected at several time points			
Data item	Number	Adjusted difference in means over time (95% Confidence Interval)	P-value
UKPDS risk score*			
6 months	157	0.5 (-1.1,2.1)	0.54
12 months	157	0.2 (-1.9,2.2)	0.87
HbA1c %	116	-0.123 (-0.578,0.333)	0.595
Total Cholesterol mmol/L	108	0.101 (-0.313,0.515)	0.629
Total Cholesterol/HDL	108	0.098 (-0.244,0.440)	0.571
Systolic blood pressure	100	-2.583 (-10.250,5.084)	0.505
Total wellbeing score	96	1.085 (-0.946,3.117)	0.292
Unpaired t-test analysis of Patient Enablement Instrument scores			
PEI score (story-sharing) Mean (SD)	PEI score (control) Mean (SD)	P-value	
8.3 (3.6)	5.9 (3.6)	0.002	

* When calculating UKPDS risk score, we sought data from clinic and GP records where participants had defaulted from follow-up. Where data were unobtainable from any source, we assumed no change from the previous value.

Data on costs are given in Table 4 below.

Table 4. Estimated costs of running BHA-led story-sharing groups

COST OF RUNNING A TRAINING COURSE FOR 12 BHA FACILITATORS			
Item	Unit cost	Number	Total
BHA attendance at training course	£50 per half day	12 half days, 12 BHAs	£7200
Course trainer input	£150 per half day	12 half days preparation/ admin, 12 half days delivery	£3600
Venue hire and refreshments	£100 per half day	12 half days	£1200
Resource pack (training manual, additional materials)	£20 per pack	1 per participant, 3 spare = 15 total	£300
External accreditation / quality control	£300 per course	1	£300
Total cost of training 12 BHAs as story-sharing facilitators			£18000
Total cost of training one BHA as a story-sharing facilitator			**£1500**
COST OF RUNNING A STORY-SHARING GROUP			
Item	Unit cost	Number	Total
BHA input to story-sharing group	£50 per half day	12 half days preparation / admin, 12 half days delivery	£1200
Session input from health professionals	£60 per hour	6 x 1-hour attendances	£360
Venue hire and refreshments	£100 per half day	12 half days	£960
Total cost of running one 12-week story-sharing course			£2520
Total cost per participant (not including training the facilitator)			£210
Total cost per participant (including training the facilitator)			**£345**

3.3 Qualitative findings I: Analysis of stories shared

3.3.1 Practical issues

A summary of the findings of the thematic analysis is given in Appendix 1. This analysis revealed seven main practical issues facing the person with diabetes: knowledge (e.g. what is a 'normal' blood glucose level), diet, exercise, medication, foot care, self monitoring, and accessing care. These map closely to the domains covered by self management education

guidelines (Funnell, Brown, Childs, Haas, Hosey, Jensen, Maryniuk, Peyrot, Piette, Reader, Siminerio, Weinger, & Weiss 2009;Khunti, Camosso-Stefinovic, Carey, Davies, & Stone 2008). Significant knowledge and skills deficits in all these domains were evident in some but not all participants, especially in relation to diabetes complications and how to prevent them. Since the findings from our thematic analysis align closely with previous research on diabetes knowledge and skills in low-literacy minority ethnic groups (Carbone et al. 2007;Chan & Molassiotis 1999;Tang et al. 2008;von Goeler et al. 2003), we have not presented them in detail here.

3.3.2 Illness storylines

Narrative analysis revealed a number of over-arching illness storylines within which the practical issues listed above acquired social meaning and moral worth.   Below, we consider the key storylines in the experience of diabetes in all the cultural groups studied.

STORYLINE 1: ENTERING THE KINGDOM OF THE SICK

"(I was) panicky, fear gripped me… I didn't think I would die but I was very frightened – I had heard about diabetes in the family. I cried for 3 days because I was frightened and everyone said to me awful things would happen to me, strokes and I don't know what… I am still frightened."

(participant in Tamil group, T1)

"I am finished, a dead man, no longer a man, no longer any good to my wife."

(group details withheld)

Almost all groups spontaneously devoted the first session to each participant in turn giving an account of when and how they had been diagnosed, and describing how they felt about this. Most had experienced shock, fear and feelings of hopelessness, loss and isolation. Many knew of others who had developed terrible complications and anticipated that they would too. In one group, for example, every participant knew someone who had had an amputation. A recurring question was whether and with whom to share the stigmatising news that diabetes had been diagnosed. Some had concealed the diagnosis from relatives (and even, in some cases, from spouse or fiancé[e]) for years. For some, going onto insulin (in the past or in the future) represented a further shock and deeper stigma.

As Susan Sontag has observed: *"Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each*

of us is obliged, at least for a spell, to identify ourselves as citizens of that other place." – page 3 (Sontag 1979).

This storyline resonates with Kleinman's suggestion that the diagnosis of serious illness generates a near-universal narrative, oriented to questions such as "Why me", "Why now?" and "What hope?" (Kleinmann 1988). It also links to Frank's concept of deep illness (*"illness is 'deep' when perceived as lasting and affecting virtually all life choices and decisions, and as altering identity"* – page 197) (Frank 1995), and to the sociological construct of liminality – embracing changed identity as well as *"a state of variable alienation from social familiars, expressed as an inability to communicate the nature of the experience of the illness, its diagnosis and treatment"* (Little et al. 1998).

STORYLINE 2: REBUILDING SPOILED IDENTITY

"My [diabetic] mother was in Saudi eating and eating inside doing nothing, watching TV all day. She wasn't well, and then she returned home to Somalia and walked a lot to visit her sisters and she ate less and was happier. She lost weight and felt much better."

(participant in Somali group, S4)

"At first I was crying and very frightened, then I got better: my doctor said go swimming, get out of the house. Now I swim every day at 7am and do yoga…..and I am 63!"

(participant in Tamil group, T1)

Much has been written about chronic illness as disrupted narrative (Bury 1985). Both Anselm Strauss and Arthur Frank have argued that identity rebuilding is the primary purpose of the illness narrative (Frank 1998;Strauss 1975). Sharing stories about illness offers the opportunity to repair spoiled identity – presenting the self as a 'good patient', 'good parent', 'good employee' and so on, struggling to cope with the challenges that illness brings.

Interestingly, we did not encounter any examples of what Frank called the 'quest' narrative (i.e. finding a new, 'heroic' identity through illness, perhaps by raising money for a research charity) of the kind that often characterise cancer or AIDS narratives. Rather, as the above quotes show, identity was rebuilt in a very practical, physical way, usually around participation in the family and community.

We believe this may be partly because symptom control in diabetes is achieved through altering the balance between energy intake and expenditure, hence is linked to regular and sustained physical activity and reduced opportunities for 'grazing'. Most of our participants were South Asian or African women who did not work outside the home and for whom

physical activity was traditionally undertaken as domestic and community duties. In the first story fragment above, the main character is depicted as resuming a traditional female role; in the second, she has 'reinvented' herself as a participant in sport and yoga, but in each account the rebuilt identity is closely linked to a shift from being indoors, sedentary and introspective to out of the home, active and linking with others.

STORYLINE 3: BECOMING A PRACTITIONER OF SELF MANAGEMENT

"They [various tablets for diabetes] are like a herd of cattle for me and I remember each one like a different cow."

(participant recently immigrated from Somalia where she lived a nomadic life herding cattle, group S4)

"When should I test [my blood], is it when the doctor says or when I want to?"

(participant in Tamil group, T3)

A recently widowed man had found it impossible to apply advice from white British dieticians to his own shopping and cooking. The women in the group had taken it upon themselves to "sort out this gentleman's meals", and had been asking him every session what he had made himself to eat. His early accounts of failure at "women's" work had led to much laughter, but in a very supportive atmosphere. The man had initially listened without comment as the women exchanged stories of their own shopping and cooking, and in this session he proudly presented a story of successfully following one of the recipes himself.

(field notes on African Caribbean group, AC7)

By far the commonest type of story told was one about the practicalities of looking after oneself with diabetes. Much tacit knowledge relating to diet, physical activity, self-monitoring and managing medication was exchanged through such stories. The quotes above show participants either seeking or providing strategies to operationalise the principles of good diabetes self management within the social and practical constraints of their daily lives.

In many groups, one or two members tended to dominate the first few sessions while the majority remained silent. This imbalance tended to resolve with time. Lave and Wenger coined the term 'community of practice' to describe a group of practitioners who share a common interest, purpose and perspective (Lave & Wenger 1991).

"Communities of practice are groups of people who share a concern, a set of problems, or a passion about a topic, and who deepen their understanding and knowledge of this area by interacting on an ongoing

basis… As they spend time together, they typically share information, insight, and advice. They solve problems. They help each other. They discuss their situation their aspirations, their needs. They think about common issues. They explore ideas and act as sounding boards to each other…. they become informally bound by the value that they find in learning together." (Wenger, McDermott, & Snyder 2002)

In such communities, learning is not about amassing socially disembodied 'facts' but about developing an identity through practice and building the social networks that form the scaffolding for tacit knowledge acquisition. Applying this theoretical model to the empirical data of this study, we can say that learning diabetes self management is not so much about acquiring knowledge and skills but about becoming a practitioner of self management.

A key concept in the communities of practice literature is 'legitimate peripheral participation' – participating silently and peripherally in group learning (e.g. saying nothing in a group or 'lurking' in an email discussion). According to Lave and Wenger, peripheral participation is the way novices acquire the complex knowledge that is tied to practice – as illustrated by the African Caribbean man who learnt to cook largely by listening to the women in his group exchanging recipes.

Largely unprompted by the facilitators, almost all groups came to include some aspect of *doing*. Some groups, for example, organised to walk together in the local park, and other groups introduced ten minutes of chair-based exercise before commencing their story-sharing. When the chosen theme was food, participants typically brought samples to share and compare, and one or two groups tried to negotiate the use of a kitchen for collective cooking sessions. After sharing stories on using blood glucose testing machines, many groups opted to test the blood glucose of all willing group members then and there. As predicted by Lave and Wenger's model, talking about self management acquired meaning through doing self management.

STORYLINE 4: LIVING A DISCIPLINED AND BALANCED LIFE

An Imam [Muslim preacher] has been invited to attend a predominantly Muslim group and advise on managing diabetes. He stresses the importance of "looking after your body which God has given you" and not fasting recklessly if you are ill (e.g. shorter fasts in the summer months; giving money to the poor instead of fasting).

(field notes on Bengali group, B4)

The [predominantly Sikh] group talks about changing traditions, the holy 'sweet' (prasaad) that is served in temples used to be made with a one-third flour, one-third ghee and one-third sugar, it used to "drip in your hands there was so much sugar". This was also a time when everything in the temples had to have equal proportions. Now they use much less ghee and sugar and also give you (or expect you to take) very small amounts

compared to before. People here are becoming much more conscious of things that are bad for you, they say.

(field notes on Urdu group, U3.4)

A fatalistic attitude from one group member ("I'm going to die anyway so why bother doing the tests or following a healthy life?") drew strong criticism from the other group members, who saw great religious value in taking control over one's diabetes and achieving balance.

(field notes on Urdu group, U4.4)

For many participants, their core identity was as a Muslim, Hindu, Sikh, or Christian, and the practice of self management was secondary to the practice of their religion. Importantly, there were common themes in both these practices – notably the notions of self-restraint, balance and observing a set of rituals. Religious foods, menus and practices were frequently discussed, and there was much negotiation on how religious rituals (especially the cycle of feasting and fasting) should be adapted to the needs of the person with diabetes and whether, more generally, religion aligned or conflicted with healthy lifestyle choices.

In all the groups (in which were represented all the great religions except Judaism), quotations were produced from the scriptures to support moderation in diet (i.e. not eating to excess and not fasting) and moderate physical activity levels, especially when the person's health specifically requires this. The above example of how the recipe of the Sikh holy sweet (and the size of a 'portion') has changed over time to respond to the rising prevalence of obesity and diabetes in the Sikh population illustrates how religion can accommodate to health need.

STORYLINE 5: MOBILISING A CARE NETWORK

"No-one actually looks after me for my diabetes, I've had it for four years and no-one cares for me…"

(participant in Bengali group, B1.1)

Whatever we learn here [in the group] I must not keep it to myself but share it with others – so when my uncle rings from India I ask have you done your cholesterol test yet? I am going to India in November and I have told my relatives I will be doing their blood tests."

(participant in Urdu group, U2.4)

Most participants described an extended lay care network which helped them with self management. Older women in particular relied on their daughters, daughters-in-law or sons to oversee medication and operate technological tools (e.g. insulin pens, blood glucose machines). The family

played an important role in encouraging the person with diabetes to remain active, control their food intake and take their medication as directed. Successful 'self' management seemed to depend not so much on whether particular knowledge or skills were present in the index patient but whether these were present in the wider care network. Those who lacked such a network perceived themselves (probably correctly) as at a huge disadvantage and were more reliant on health professionals.

Annemarie Mol, using empirical examples from diabetes management, has argued that 'the logic of care' typically involves not just the self-managing patient but also a network of health professionals and family members, supported by point-of-care technologies, whose input must be flexible and responsive to the person's condition (Mol 2008). For the engaged, active and motivated patient, the care network may be relatively quiescent, but during periods of acute exacerbation or for the chronically sick or disempowered, the patient may play a passive role and rely heavily on others. Given the inexorable progression in the natural history of diabetes, the ability to mobilise and draw upon a rich network of lay carers is a key element of self management, especially in the longer term.

STORYLINE 6: NEGOTIATING ACROSS A POWER GRADIENT

"He just says you are not taking your tablets properly whatever is wrong with me, but I am taking them properly"

(participant in Urdu group, U1.2)

One participant has been begging him [GP] to prescribe exercise on prescription but he won't. "He says he is not allowed to". [Note: all GPs in the borough can prescribe exercise but they have to pay for it from the practice budget]

(field notes on Urdu group, U2.4)

"Sometimes we get too frightened to ask the doctor [consultant] or specialist nurse."

(participant in Bengali group, B5)

"When insisting on seeing the GP, always be polite to the receptionists".

(participant in Urdu group, U4.6)

Functional health literacy includes practical knowledge about how to communicate and negotiate with healthcare staff (Nutbeam 2000). Limited English speakers faced a substantial power differential in their encounters with both receptionists and clinicians (a finding we observed in a previous

study of limited English speakers in London (Greenhalgh, Robb, & Scambler 2006)). Many stories depicted a heroic struggle to gain access to clinicians, achieve particular outcomes (such as tests or self-management resources) or challenge the assertion that one is a 'bad patient' (what Goffman has called 'face work' (Goffman 1969)). Often, the person knew what to do but lacked negotiating power in a system oriented to maximising "efficiency" (i.e. minimising resource use). Many were ignorant of the free interpreting and advocacy services available in the borough. In response to these stories, group members suggested various negotiating tactics.

STORYLINE 7: MANAGING THE MICRO-MORALITY OF SELF-CARE 'CHOICES'

A woman with painful feet told the group that she had recently been given a plug-in footbath as a birthday present by her daughter. As the story unfolded it became clear that she was well aware of the dangers of applying external heat to neuropathic feet, and had not actually used the footbath. The problem was that the footbath had been expensive and the daughter was poor. The group joined in a discussion of whether it was reasonable to 'reject' the birthday present in these circumstances.

(field notes; group details withheld)

A podiatrist arrived with flash cards and a powerpoint presentation. The BHA politely asked her not to show these but instead listed to the stories offered by the group. As the BHA translated the stories, it became evidence that all the participants had heard the 'foot care' talk before, but they were still confused. One woman pointed to her own shoes and those of her neighbour. "I was told to buy these special shoes for £80", She said, "but she was told to go to the shop on the high street and buy those shoes for £20. They look pretty much the same. Why was I given different advice?"

(field notes; group details withheld)

The experience of being poor pervaded many stories. The choices associated with self management were characterised by a complex micro-morality which required trade-offs between perceived health-promoting investments (e.g. shoes for oneself) and other life projects and concerns (e.g. food for the family). As in the first example above, large amounts of money were sometimes spent by the patient or wider care network on folk remedies (traditional or contemporary) that were ineffective or harmful.

Narratives have an ethical dimension: not only do they depict 'good acts' and 'evil acts', but more subtly, they show how much of lived experience is a struggle between 'better' or 'worse' moral choices, and how human virtues such as courage, humility, loyalty or thrift can overcome vices such as selfishness or malice (Nussbaum 2001;Ricoeur 1984). As botht he foot care examples above show, people are often well aware of healthy lifestyle

advice but must decide, taking account of cultural roles and expectations and economic realities, what they 'should' do in particular social situations.

An important dimension of self management choices is their situated and contingent nature. The participant in the footbath example did not want abstract advice on whether footbaths should be used 'in general' (she already knew the answer to that question) or whether it was ever right to reject any birthday present. Her practical and moral dilemma was whether to reject this birthday present, given these particular personal circumstances. The dilemma was resolved when it emerged (in response to questions from group members) that another family member had a birthday coming up and was interested in receiving the footbath. Similarly, the woman who confronted the podiatrist about the cost of shoes was not interested in 'shoes in general' but whether *these* shoes had been worth the extra cost!

The example of the podiatrist being challenged about the cost of shoes also illustrates how the power dynamics of communication are profoundly different in a story-sharing group compared to a clinical consultation. It is unlikely that an illiterate, non-English speaking patient from a low socio-economic background would have felt it appropriate or even possible to challenge the podiatrist about the cost-effectiveness of a specialist product in a clinic setting. But in the story-sharing group, this was one of the first stories to be raised, and it was raised confidently. The philosopher Jurgen Habermas developed a theory of communicative action, arguing that open and honest communication is unlikely to occur when there are severe time constraints and large power inequalities between the speakers; we have shown that this is typically the case in consultations between limited English speakers and doctors or nurses (Greenhalgh, Robb, & Scambler 2006). The story-sharing group reverses the power dynamic and also provides sufficient time and sanction for the sharing of matters that might be dismissed as trivial or irrelevant in a consultation. Hence, the micro-morality of 'choices' comes to be 'in-frame' rather than 'out-of-frame'.

STORYLINE 8: TAKING COLLECTIVE ACTION

A group of Muslim Bangladeshi women shared stories of how difficult it was for them to take exercise in parks or swimming pools because of social disapproval. They decided that as taxpayers, they were entitled to women-only swimming sessions at the local pool, and went along to ask for these. The pool managers agreed to allocate some sessions, but then the women realised they did not have appropriate clothing to protect their modesty while swimming. They decided to make swimming dresses at home, and those without sewing machines made contacts from within the group to share resources.

(data from evaluation report by BHA leading Bengali groups)

As well as sharing individual stories orally, groups also became involved in what Victor Turner has called social drama – that is, the unfolding of collective action with a strong sense of common purpose (Turner 1980). Mattingly has emphasised the 'healing drama' of a positive personal story, in which enacting one's story to the protected audience of the group (for example, by reading out letters or passing round a bottle of tablets), and experiencing the audience's emotional response, becomes part of the healing process (Mattingly 1998).

Collective action outside the group was sometimes characterised by what Paulo Freire has called 'critical consciousness' (i.e. through education, participants had become conscious of injustice and keen to overcome it) (Freire 1974), especially when they discovered a mismatch between what diabetes care they were entitled to and what they were actually receiving. More commonly, collective action had little or no overt political dimension but provided a strong sense of solidarity which served as a link between wanting to behave in a particular way and actually achieving this.

As an overall, commentary on this dataset, the commonalities in illness storylines between different cultural groups were far more striking than their differences. The triple jeopardy of immigrant status, material poverty and low functional health literacy is well described in the literature and poses a huge challenge to health educators (Kreps & Sparks 2008;Tang, Pang, Chan, Yeung, & Yeung 2008;Zanchetta & Poureslami 2006); the stories shared helps illuminate how this triple jeopardy impacts on the process and outcome of self management.

3.3.3 The pedagogical value of story-sharing

"*I knew from the doctor, he told me to take my medicine and eat less but I didn't understand properly, and he didn't have the time to explain. Coming to the group I understood and from other people here and in my own language talking about it. Also I am going to learn English now so I can communicate better!*"

(participant in Somali group, S4)

"*We learn the facts from you [health professionals] but we learn the meaning and how to do things from one another*"

(participant in Bengali group, B1.7)

"*Come to the group to learn what questions to ask*"

(participant in Urdu group, U2.3)

Most participants in this group had had limited formal education. Many did regular blood tests (up to three times a day) but admitted that they did not understand or act on the results. Sharing stories within the group appeared to prompt reflection on why the tests were being done and what particular values meant.

(field notes; group details withheld)

As the above quotes and field notes show, sharing stories in an informal group setting was perceived by participants and staff to have great pedagogical value. The reasons for this are considered in the Discussion (Section 4.2.1).

3.4 Qualitative findings II: Process evaluation

In the evaluation sessions, most participants in the story-sharing groups emphasised the social nature of the group, describing it as an "enjoyable" and "supportive" way of learning. As illustrated in the previous section, they also emphasised the practical knowledge gained and its link with action. The most common change cited by participants as a result of attending the group was reducing the amount of fat in the diet (usually as a result of exchanging recipes); other changes included exercising more and getting out of the house more. Many participants described themselves as more confident and some said they were now keen to learn English "so as to communicate better".

The BHAs and lay facilitators felt that the greatest benefits of the group had been gains in participants' practical knowledge and skills; and in some participants, a 'transformational' change characterised by greatly increased motivation, confidence and hope for the future. In such individuals, membership of the group appeared to have led to much wider 'empowering' – for example many participants had been almost housebound and used hospital transport routinely to attend outpatient appointments; after attending the group they became confident in using public transport and began to develop interests and activities outside the home (including, for some, signing up for English lessons for the first time).

A full list of points raised in the evaluation of the groups is given in Appendix 2.

3.5 Embedding the intervention within an NHS service

The service model of story-sharing groups was popular with both staff and patients from the outset. Importantly, it was also popular amongst senior clinicians and managers. For example, the Trust chief executive had attended some story-sharing groups in a pilot phase of the study and was a co-applicant on the funding bid.

In process interviews, a key success factor was thought to be the skilled input of various senior staff, especially the Consultant Diabetologist, to get the project on the agenda of different boards, committees and working groups both in the hospital and the wider community, so that the study became a rolling agenda item in key decision-making groups.

The sharing stories model required a fundamental change in the role of the BHA and considerable adjustment in working relationships. In particular, BHAs had to move from 'didactic teacher' and 'passive translator' roles to 'facilitator of peer learning'. This involved valuing the stories shared and using these as the basis for leading reflection and discussion, as well as inviting visiting health professionals to comment on these stories rather than give a prepared speech. Whilst a 12-week training programme was helpful, the BHAs or lay facilitators were initially under-confident in their new role, though this improved dramatically as they gained experience.

In the original plan, it was envisaged that BHAs and facilitators would contact health professionals (consultants, podiatrists, dieticians, diabetes specialist nurses) and ask them to attend group sessions as needed. In reality, this proved unworkable, due to a combination of lack of confidence, limited time, and (in some) weak project management skills. In this study, these administrative aspects were taken over by the research nurse, though a senior project manager could have fulfilled this role.

There was evidence of an interesting phenomenon of reciprocity: when a health professional attended a story-sharing group, this appeared to generate some intangible currency within the organisation in terms of goodwill elsewhere in the system. For example, if a podiatrist attended the session an invitation might follow for a consultant or diabetes specialist nurse to give a seminar to the podiatrists about diabetes, and these requests were honoured as much as was practicable.

Conversely, the story-sharing groups provided payback to the organisation in unanticipated ways – for example, medical students attached to the Trust were sent to the groups to learn about the patient experience. These subtle but important moves helped to embed the innovative service model into the business-as-usual of a busy acute Trust. However, this informal approach was probably only possible because of the relatively small scale of the intervention, which typically only had one or two groups running in any particular week, and hence raises questions about the scalability of the model.

Considerable interpersonal work was needed to engage GPs to attract referrals to the study and work with the PCT diabetes nurses to operationalise referrals to the 'usual care' control intervention. Whilst most community staff were broadly positive about the study, there was some anxiety about an initiative to evaluate an existing service against a background of restructuring, financial pressure and frozen posts. In other words, even those who signed up to the academic goal of finding generalisable truths about the superiority or otherwise of BHA-led story-sharing groups versus nurse-led standard education groups were still aware that the findings of the study could have a direct and adverse impact on their own roles and jobs. To some extent, these concerns were overcome by interpersonal contact between NHS staff on the POSEIDON project and the nurses, BHAs and managers in the PCT.

In terms of service user input to the governance of the study, three key messages were fed back. The first was that nobody liked the randomised trial design, especially when they were allocated to the control group. Staff and users were so positive about the story-sharing groups that being randomised to 'usual care' met with palpable disappointment. This may of course have been a Hawthorne effect relating to a newly introduced service that had been widely publicised, but it was clear that most users failed to see the significance of randomisation and wanted everyone to have the 'benefits' of the intervention.

The second message from users was that many of those who had attended the story-sharing groups wanted them to continue. Story-sharing groups began in the action research phase of the study as 'drop-in' sessions in voluntary sector organisations (Greenhalgh, Collard, & Begum 2005b). In this format, length of attendance had been very variable, with some people attending just once or twice and others becoming regular members and actively recruiting their friends and family. When the groups became a time-limited 'intervention' rather than a community resource to be drawn on as and when needed, it was perhaps unsurprising that some attenders would leave the group after a few sessions while others were still keen for more after 12 sessions. Hence, whilst our designated user 'advisers' had little to say about the governance of the study, they were crucial in providing the user pressure on the Trust to keep the groups going on mainstream funding after the end of the study period.

Finally, service users recognised the power of story-sharing and actively looked for opportunities to pass their learning on to others outside the group. Largely on their own initiative, for example, some group participants volunteered for the 'Patient Voices' initiative whereby people make video and DVD versions of their illness story as a resource for others (see www.patientvoices.org.uk).

4 Discussion

4.1 Summary of main findings

4.1.1 Quantitative findings

In terms of quantitative findings, this study has demonstrated that a new model for self management education in minority ethnic groups with diabetes, based on the sharing of personal stories in facilitated own-language groups, was more popular, better attended and led to significantly greater patient enablement than standard structured education in nurse-led groups. The enthusiasm and commitment of local NHS clinicians and managers allowed the story-sharing intervention to be successfully embedded in a busy diabetes service with high levels of attendance and follow-up. Despite this, impact on clinical and biochemical outcomes and wellbeing in the target population was minimal.

4.1.2 Qualitative findings

The qualitative analysis of the participants' illness narratives revealed two levels of findings. Thematic analysis confirmed the findings of previous work that there are seven practical issues facing the person with diabetes: knowledge, diet, exercise, medication, foot care, self monitoring and accessing care. These map closely to guidelines for self-management education, and significant knowledge and skills deficits were evident in some participants. Narrative analysis revealed a number of illness storylines within which these practical issues acquired social meaning and moral worth: entering the kingdom of the sick, rebuilding spoiled identity, becoming a practitioner of self management, living a disciplined and balanced life, mobilising a care network, negotiating across a power gradient, managing the micro-morality of self-care 'choices', and taking collective action. In the context of low health literacy and socio-economic deprivation, much of the biographical work needed for successful self management appears to be oriented to resolving conflicts between the Voice of Medicine (what health professionals expect of a 'good' self-managing patient) and the Voice of the Lifeworld (what family and community expect, and the structural constraints which place limits on possibilities) (Mishler 1984).

4.2 Interpretation of findings

4.2.1 Explaining the positive subjective experience of the story-sharing groups

It seems that despite the limited impact on clinical outcomes, participants perceived themselves to be getting something important out of the story-sharing group. Theoretically at least, the group provides opportunities for making sense of experience (Bruner 1990;Strauss 1975;Vygotsky 1979), transmitting and personalising tacit knowledge (Polanyi 1962), social modelling (Bandura 1977), participating in a community of practice (Lave & Wenger 1991), developing social networks and capital (Putnam 2000), enacting 'healing drama' (Mattingly 1998), and developing critical health literacy (Friere 1974;Nutbeam 2000) – and this is by no means an exhaustive list. Given these multiple theoretical mechanisms of action, it was disappointing that this was not translated into a significant clinical bottom line, though this finding should be interpreted in the light of the limited impact of other widely used diabetes education models on comparable populations compared with control interventions (Davies, Heller, Skinner, Campbell, Carey, Cradock, Dallosso, Daly, Doherty, Eaton, Fox, Oliver, Rantell, Rayman, & Khunti 2008;Lindstrom et al. 2008).

The sharing stories model was developed specifically to address the needs of limited English speakers with diabetes living in deprived inner-city areas. Being poor is stressful and consistently produces adverse health outcomes by increasing both susceptibility and risk (Marmot & Brunner 2001). Chronic illness brings poor functional capacity as well as shame and rejection, generating a vicious circle of insecurity, loss of confidence and social isolation (Jordan & Osborne 2007;Osborne, Jordan, & Rogers 2008). Diabetes prevalence and outcomes are dramatically skewed by socio-economic status (Bernard, Banthin, & Encinosa 2006;Gnavi et al. 2008;Gulliford, Mahabir, & Rocke 2004;Thomas, Hypponen, & Power 2007). 'Ethnic' inequalities in diabetes are greatly reduced when confounders like socio-economic status, health literacy, adherence to medication, and access to care are controlled for (Bhopal et al. 2002;Garcia & avides-Vaello 2006;Heisler et al. 2007;Millett et al. 2007;Schillinger et al. 2002).

Poor immigrant patients may be unable to speak English fluently, and may have low health literacy in their own language, both of which increase social distance, reduce communication, and threaten trust between patient and health professional (Greenhalgh, Robb, & Scambler 2006;Nutbeam 2000;Putnam 2000;Robb & Greenhalgh 2006). Whilst efforts are being made to redress inequalities in access to diabetes care (Cooper, Hill, & Powe 2002;Millett, Saxena, Ng, Mainous, III, & Majeed 2007;Rabi et al. 2006), it is a fact of life that those with greater social and cultural capital are better able to 'get on' in the social world (Bordieu & Passeron 1990). Amongst the poor and disadvantaged, 'self management' may be as much about building social capital and developing strategies to overcome structural barriers to positive health outcomes (e.g. poor access to services, high cost of healthy food, lack of safe places to exercise) as it is about a self-care skill set

(Snoek 2002;Vijan et al. 2005;Wann 1995). For all these reasons, facilitated story-sharing has particular theoretical benefits in the poor and disadvantaged.

There are numerous possible reasons why the story-sharing groups were seen as rich environments for learning. The group provides opportunities for making sense of experience. As Bruner has argued, much of life is narratively structured, and telling stories allows us to find meaning (and hence sensemaking) in what has happened (Bruner 1990). The story is a powerful vehicle for transmission and personalisation of tacit knowledge – a fact that is well illustrated by the difference between trying to follow a recipe from a cookery book compared to hearing someone describe how they *actually* cooked that dish (Polanyi 1962). As Bandura showed, adults learn through social modelling (seeing someone do something), and the enacted story can be seen as a form of this (Bandura 1977).

In common with others who have researched low-literacy minority ethnic groups (Carbone, Rosal, Torres, Goins, & Bermudez 2007;Chan & Molassiotis 1999;Tang, Pang, Chan, Yeung, & Yeung 2008), this study found that an individual's ability to self-manage was largely unrelated to their level of abstract knowledge about diabetes. Participants instinctively recognised the distinction between abstract knowledge ('knowing-that'), which they felt they gained from health professionals, and practical understanding ('knowing-how'), which they felt they gained from sharing stories. This resonates strongly with many established pedagogical models – for example, Polanyi's theory of personal knowledge (Polanyi 1958); Vygotsky's emphasis on the socio-cultural embeddedness of knowledge and the central role of spoken language in cognitive development (Vygotsky 1986); and the distinction between 'mode 1' and 'mode 2' knowledge in science and research (Gibbons et al. 1994).

4.2.2 Explaining the negative impact of the group on quantitative outcomes

The lack of significant impact on clinical risk or outcome has a number of possible explanations. It may be due to simple lack of efficacy of story-sharing as an educational tool, or it may be that the intervention period was too short and/or that there was insufficient time for the participants to put their learning into practice before outcomes were measured (Loveman, Frampton, & Clegg 2008a).

However, our data are also consistent with the conclusion that the potential of the story-sharing model to improve outcome was unfulfilled because it was inadequately optimised as a complex intervention. This interpretation is supported by two recent publications. First, the story-sharing experience in this study was not systematically coupled to individual goal setting or care planning – a link which others have recently shown can improve outcomes in diabetes peer support and education programmes (Loveman, Frampton, & Clegg 2008a;McCormack et al. 2008). Second, the emphasis on

'unstructured' story-sharing may have meant that some groups failed to cover the key learning domains which Osborne et al have recently identified for holistic education in chronic illness (Osborne, Elsworth, & Whitfield 2007). This is discussed further in Section 4.4 below.

4.3 Strengths and limitations of the study

4.3.1 The tension between 'developmental' and 'experimental' study designs

This study builds on many years of action research in a socio-economically deprived, multi-ethnic community that has previously been described as 'hard to reach'. Buy-in to the idea of story-sharing was already high when we began the randomised trial phase, and this had both advantages and disadvantages. On the one hand, there was much enthusiasm for the work and the model, which, being 'locally grown', had high credibility with stakeholders. The enthusiasm and commitment of clinicians and managers allowed this complex intervention to be successfully embedded in a busy NHS service with high levels of attendance and follow-up.

On the other hand, few front-line staff were in clinical equipoise about the efficacy of the intervention, and this made the trial difficult to operationalise. Whilst research-trained nurses and managers saw the importance of presenting the options impartially while seeking informed consent, lay staff and BHAs sometimes found this task difficult to grasp. The clinical role of the BHA is to explain the different service options to the patient, ascertain her choices, and ensure that these choices are met as far as possible. We under-estimated the degree of role conflict that the BHAs would encounter when the key question changed to "you won't have a choice, are you willing to be randomly allocated to one of two different service models?" Early in the study, we were approached by BHAs who felt that the study design was unethical ("the lottery of randomisation"). We overcame their by using bank interpreters (sessional bilingual staff who took a 'translator' rather than 'advocacy' role) for the initial visit and consent process.

We are not alone in encountering tensions encountered between the action research and randomised trial phases of complex intervention research. In a programme of research on peer support in breast-feeding, Hoddinott et al followed a similar multi-phase design, commencing with exploratory, qualitative studies (Hoddinott & Pill 1999;Hoddinott & Pill 2000), progressing to an action research phase (Hoddinott, Lee, & Pill 2006;Hoddinott, Pill, & Chalmers 2007;Hoddinott, Pill, & Hood 2000), and then undertaking a randomised controlled trial (Hoddinott et al. 2009). Whilst the qualitative studies provided good theoretical reasons why peer support might work, and the action research work pointed to a positive impact of peer support in breastfeeding, the randomised trial produced negative results. Reflecting on these, the authors commented, *"The*

preliminary study used action research methods, compared with a distant research team running a trial, and partnership working between midwives, health visitors, and women was less evident in the trial" (Hoddinott, Britten, Prescott, Tappin, Ludbrook, & Godden 2009).

Hoddinott's findings, which resonate closely with our own, raise interesting epistemological questions about the status of the randomised trial as the 'gold standard' in evaluating the impact of policies that are likely to depend heavily on building a positive institutional context within which the core intervention can be embedded. In both studies, the mismatch between action research and trial findings may have been due partly to a distinct fall in staff enthusiasm when they were required to take on a position of clinical equipoise in relation to an intervention they had already invested in emotionally and professionally.

4.3.2 The language barrier between researchers and participants

The qualitative findings on key themes in self-management and over-arching illness storylines must be interpreted in the light of limitations in our method. Since naturally-occurring talk cannot be audiotaped without interfering with the social situation, there is an inherent trade-off between the authenticity of the story (particularly its informality and spontaneity) and the accuracy with which it can be recorded. The quotes reproduced in Section 3.3 are verbatim where quotation marks are used. However, in most cases they are not the original words of the narrator but a translation (and perhaps, re-telling) by a BHA or another group member. More significantly, because of the language barrier, we estimate that we only captured around ten percent of all the stories told in 58 of the 65 groups.

We do not know precisely what led BHAs and other bilingual participants to translate some but not other stories for the researcher, though in some cases we observed participants indicating to the BHA that a particular story should be translated. On the one hand, this selective translation (and the researcher's monolingual status) was a positive feature of the study design as it allowed the group to control and even negotiate what was to be shared as 'data'; on the other hand it almost certainly introduced a systematic bias in the dataset which could be reduced in future studies by using bilingual researchers.

4.3.3 The tension between 'structured' and 'unstructured' education

It is a 'truth universally acknowledged' that structured education is the gold standard in diabetes education. Yet a defined feature of the core component of the intervention was that the story-sharing should be spontaneous and *unstructured*. We believe that both structured and unstructured formats each have strengths and weaknesses. In relation to

structured education, a formal checklist of knowledge and skills ensures that all key domains are covered, but conveying these in a classroom setting with insufficient attention to meaning and context may produce limited impact in the person's life. An unstructured format, on the other hand, lessens the dominance of the professional agenda and allows people to raise all the issues that are important and worrying for them, but may leave critical stones unturned.

We believe our qualitative data may have revealed a significant finding here, though at this stage we express it as a provisional hypothesis. The thematic analysis revealed seven practical domains around which diabetes self management education might reasonably be structured. But the diabetes storylines which appear to be common to many if not all ethnic groups have reveal an additional educational need: the domains of structured education must be embedded in personal stories before they begin to acquire social meaning and moral worth. This may be best achieved by inviting *unstructured* storytelling using the practical domains as prompts.

4.4 Implications for practice, policy and further research

4.4.1 Practice and policy

Whilst the findings of this study are preliminary, we believe our data supports two key developments in the design and delivery of self management education programmes. First, such programmes should take closer account of the over-arching storylines that appear to pattern the experience of chronic illness in the poor and disempowered. And second, they should be more firmly grounded in the pedagogical distinction between the 'mode 1' domain (knowledge that is formal, codifiable, transferred as 'facts', and measured as performance in tests) and the 'mode 2' domain (knowledge that is informal, embodied, tied to practice and context, transferred through storytelling and modelling, and measured as successful application in a real-world context).

4.4.2 Future research

As discussed in Section 4.2.2 above, the relatively weak and unsystematic link between clinical care planning and story-sharing groups was revealed to be a deficiency of the complex intervention in the course of this trial. Given that we have shown equivalent clinical outcomes to those achieved with structured group education from the story-sharing groups in this population, there is no ethical need for a 'usual care' control arm. Rather, we believe that the focus of further research should be to optimise the story-sharing intervention and embed it closely in the wider diabetes service not just 'in

general' (at a departmental and inter-organisational level) but on a patient-by-patient basis. In a future randomised trial, therefore, the control arm might be the model used in the intervention arm of POSEIDON – 'usual care' care planning plus an invitation to attend a story-sharing group. The intervention arm might be *enhanced* care planning comprising a patient held record card with space for all parties to write free text.   Clinicians might enter issues raised in the consultation which they feel would benefit from discussion in the story-sharing group (e.g. fear of going on to insulin, learning needs in relation to cooking), while the BHA or facilitator leading the group might enter clinical issues to be taken back to the GP, practice nurse, dietician, diabetes nurse and so on (e.g. wishes to discuss side effects of tablets). The patient could enter their own comments and friends or relatives could also contribute, especially if the patient was unable to read or write.

Another aspect of the complex intervention which should be explored further in future research is the 'structured education'-'unstructured stories' tension discussed in Section 4.3.3. We plan to refine the story-sharing intervention by developing prompts that will allow facilitators to invite stories on particular themes without seeking to control the form or content of those stories. Hence, the education would comprise a structured topic list for the group facilitator but retain the requirement for participants to tell their own stories in an unstructured way.

We hope to secure funding to refine the intervention before undertaking a further trail – perhaps of this 'enriched' story-sharing design against the original model tested in this trial.

One final direction for future research is methodological, and concerns the developmental-experimental tension discussed in Section 4.3.1 – evidence-based medicine's 'hierarchy of evidence' (Guyatt et al. 1995). We believe that in addition to further empirical work on story-sharing in diabetes, the time is ripe for a programme of *methodological* research to develop and challenge the existing wisdom on what are currently referred to as 'complex interventions'. Arguably, the latest Medical Research Council guidance, which sets out a series of phases in complex intervention research (Craig, Dieppe, Macintyre, Michie, Nazareth, & Petticrew 2008), remains wedded to a positivist and determinist world view which assumes that neat 'policy on, policy-off' comparisons are both desirable and valid, and that 'context' can be reduced to a series of fixed-effect mediators and moderators. This approach, whilst certainly the dominant perspective within health services research, has vocal critics, many of whom have proposed theoretical models of learning and change which rest on non-positivist assumptions, such as social movement theory (Bate, Robert, & Bevan 2004), social ecology theory (Glass & McAtee 2006), social realism (Pawson & Tilley 1997), and actor-network theory (Mol 2008). It is beyond the scope of this report to explore these alternative perspectives in detail. In short, their philosophical basis is incommensurable with the assumptions underpinning the randomised controlled trial. Whether the sharing stories model of care should be taken forward by further randomised trials or by more radical

research approaches is a question that cuts to the core of contemporary debates in health services research.

References

Bakhtin, M. 1981, "Discourse in the novel," in *The Dialogic Imagination. Four essays by M.M. Bakhtin.*, M. Holquist, ed., University of Texas Press, Austin, Texas.

Bandura, A. 1977, *Social learning theory* Prentice-Hall, Englewood Cliffs, New Jersey.

Bate, P., Robert, G., & Bevan, H. 2004, "The next phase of healthcare improvement: what can we learn from social movements?", *Qual.Saf Health Care*, vol. 13, no. 1, pp. 62-66.

Bernard, D. M., Banthin, J. S., & Encinosa, W. E. 2006, "Health care expenditure burdens among adults with diabetes in 2001", *Med Care*, vol. 44, no. 3, pp. 210-215.

Bhopal, R., Hayes, L., White, M., Unwin, N., Harland, J., Ayis, S., & Alberti, G. 2002, "Ethnic and socio-economic inequalities in coronary heart disease, diabetes and risk factors in Europeans and South Asians", *J Public Health Med*, vol. 24, no. 2, pp. 95-105.

Bordieu, P. & Passeron, J. C. 1990, *Reproduction in education, society and culture* Sage, London.

Bruner, J. 1990, *Acts of Meaning* Harvard University Press, Cambridge.

Bury, M. 1985, "Chronic illness as biographical disruption", *Sociol.Health Illn.*, vol. 4, pp. 167-182.

Campbell, M., Fitzpatrick, R., Haines, A., Kinmonth, A. L., Sandercock, P., Spiegelhalter, D., & Tyrer, P. 2000, "Framework for design and evaluation of complex interventions to improve health.", *BMJ*, vol. 321, no. 7262, pp. 694-696.

Carbone, E. T., Rosal, M. C., Torres, M. I., Goins, K. V., & Bermudez, O. I. 2007, "Diabetes self-management: perspectives of Latino patients and their health care providers", *Patient.Educ.Couns.*, vol. 66, no. 2, pp. 202-210.

Chan, Y. M. & Molassiotis, A. 1999, "The relationship between diabetes knowledge and compliance among Chinese with non-insulin dependent diabetes mellitus in Hong Kong", *J.Adv.Nurs.*, vol. 30, no. 2, pp. 431-438.

Chodosh, J., Morton, S. C., Mojica, W., Maglione, M., Suttorp, M. J., Hilton, L., Rhodes, S., & Shekelle, P. 2005, "Meta-analysis: chronic disease self-

management programs for older adults", *Ann.Intern.Med*, vol. 143, no. 6, pp. 427-438.

Chowdhury, A. M., Helman, C., & Greenhalgh, T. 2000, "Food beliefs and practices in British Bangladeshis with diabetes: an ethnographic analysis", *Medical Anthropology*, vol. 7, pp. 209-226.

Cooper, L. A., Hill, M. N., & Powe, N. R. 2002, "Designing and evaluating interventions to eliminate racial and ethnic disparities in health care", *J Gen Intern.Med*, vol. 17, no. 6, pp. 477-486.

Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I., & Petticrew, M. 2008, "Developing and evaluating complex interventions: the new Medical Research Council guidance", *BMJ*, vol. 337, p. a1655.

Davies, M. J., Heller, S., Skinner, T. C., Campbell, M. J., Carey, M. E., Cradock, S., Dallosso, H. M., Daly, H., Doherty, Y., Eaton, S., Fox, C., Oliver, L., Rantell, K., Rayman, G., & Khunti, K. 2008, "Effectiveness of the diabetes education and self management for ongoing and newly diagnosed (DESMOND) programme for people with newly diagnosed type 2 diabetes: cluster randomised controlled trial", *BMJ*, vol. 336, no. 7642, pp. 491-495.

Doig, G. S. & Simpson, F. 2005, "Randomization and allocation concealment: a practical guide for researchers", *Journal of Critical Care*, vol. 20, no. 2, pp. 187-191.

Donaldson, L. 2003, "Expert patients usher in a new era of opportunity for the NHS", *BMJ*, vol. 326, pp. 1279-1280.

Donovan, J. & Sanders, C. 2005, "Key issues in the analysis of qualitative data in health service research," in *Handbook of health research methods*, A. Bowling & S. Ebrahim, eds., Open University, New York, pp. 515-532.

Duckworth, W., Abraira, C., Moritz, T., Reda, D., Emanuele, N., Reaven, P. D., Zieve, F. J., Marks, J., Davis, S. N., Hayward, R., Warren, S. R., Goldman, S., McCarren, M., Vitek, M. E., Henderson, W. G., & Huang, G. D. 2009, "Glucose control and vascular complications in veterans with type 2 diabetes", *N.Engl.J Med*, vol. 360, no. 2, pp. 129-139.

Feathers, J. T., Kieffer, E. C., Palmisano, G., Anderson, M., Janz, N., Spencer, M. S., Guzman, R., & James, S. A. 2007, "The development, implementation, and process evaluation of the REACH Detroit Partnership's Diabetes Lifestyle Intervention", *Diabetes Educ*, vol. 33, no. 3, pp. 509-520.

Foster, G., Taylor, S. J., Eldridge, S. E., Ramsay, J., & Griffiths, C. J. 2007, "Self-management education programmes by lay leaders for people with chronic conditions", *Cochrane Database Syst Rev* no. 4, p. CD005108.

Frank, A. 1995, *The Wounded Storyteller: Body, Illness, and Ethics* University of Chicago Press, Chicago.

Frank, A. 1998, "Just listening: narrative and deep illness", *Families, Systems and Health*, vol. 16, pp. 197-216.

Freire, P. 1974, *Education for critical consciousness* Continuum, New York.

Friere, P. 1974, *Education for critical consciousness* Continuum, New York.

Funnell, M. M., Brown, T. L., Childs, B. P., Haas, L. B., Hosey, G. M., Jensen, B., Maryniuk, M., Peyrot, M., Piette, J. D., Reader, D., Siminerio, L. M., Weinger, K., & Weiss, M. A. 2009, "National standards for diabetes self-management education", *Diabetes Care*, vol. 32 Suppl 1, p. S87-S94.

Garcia, A. A. & avides-Vaello, S. 2006, "Vulnerable populations with diabetes mellitus", *Nurs.Clin.North Am*, vol. 41, no. 4, pp. 605-23, vii.

Gibbons, M., Limoges, C., Nowotny, H., Schwartzman, P., Scott, P., & Trow, M. 1994, *The New Production of Knowledge: The Dynamics of Science and Research in Contemporary Societies* Sage, London.

Glass, T. A. & McAtee, M. J. 2006, "Behavioral science at the crossroads in public health: extending horizons, envisioning the future", *Soc Sci Med*, vol. 62, pp. 1650-1671.

Gnavi, R., Karaghiosoff, L., Costa, G., Merletti, F., & Bruno, G. 2008, "Socio-economic differences in the prevalence of diabetes in Italy: The population-based Turin study", *Nutr.Metab Cardiovasc.Dis.*

Goffman, E. 1969, *The Presentation of Self in Everyday Life* Penguin, NY.

Greenhalgh, T., Chowdhury, A. M., & Wood, G. 2005a, "'Big is beautiful'? A survey of body image perception and its relation to health in British Bangladeshis with diabetes", *Psychology, health and medicine (In press, accepted August 2004)*, vol. 00, p. 00.

Greenhalgh, T., Chowdhury, A. M., & Wood, G. 2005b, "Story-based scales: Development and validation of questionnaires to measure well being and cultural adherence in British Bangladeshis with diabetes", *Psychology, health and medicine*, vol. in press.

Greenhalgh, T. 2002, "Integrating qualitative research into evidence based practice: development and evaluation of a complex intervention in diabetes", *Endocrinol.Metab Clin.North Am.*, vol. 31, no. 3, pp. 583-601, ix.

Greenhalgh, T. 2009, "Patient and public involvement in chronic illness: beyond the expert patient", *BMJ*, vol. 338, p. b49.

Greenhalgh, T. & Collard, A. 2003, *Sharing stories - a new approach to multiprofessional training in diabetes care* BMJ Publishing Group, London.

Greenhalgh, T., Collard, A., & Begum, N. 2005a, "Narrative based medicine: An action research project to develop group education in diabetes for health advocates and 'hard to reach' service users", *Practical Diabetes International*, vol. 22, pp. 125-129.

Greenhalgh, T., Collard, A., & Begum, N. 2005b, "Sharing stories: complex intervention for diabetes education in minority ethnic groups who do not speak English", *BMJ*, vol. 330, pp. 628-633.

Greenhalgh, T., Helman, C., & Chowdhury, A. M. 1998, "Health beliefs and folk models of diabetes in British Bangladeshis: a qualitative study", *BMJ.*, vol. 316, pp. 978-983.

Greenhalgh, T., Robb, N., & Scambler, G. 2006, "Communicative and strategic action in interpreted consultations in primary health care: A Habermasian perspective", *Soc Sci Med*, vol. 63, pp. 1170-1187.

Greenhalgh, T., Robert, G., Macfarlane, F., Bate, P., & Kyriakidou, O. 2004, "Diffusion of innovations in service organisations: systematic literature review and recommendations for future research", *Millbank Quarterly*, vol. 82, pp. 581-629.

Greenhalgh, T., Russell, J., & Swinglehurst, D. 2005, "Narrative methods in quality improvement research", *Qual Saf Health Care*, vol. 14, no. 6, pp. 443-449.

Gulliford, M. C., Mahabir, D., & Rocke, B. 2004, "Diabetes-related inequalities in health status and financial barriers to health care access in a population-based study", *Diabet.Med*, vol. 21, no. 1, pp. 45-51.

Guyatt, G. H., Sackett, D. L., Sinclair, J. C., Hayward, R., Cook, D. J., & Cook, R. J. 1995, "Users' guides to the medical literature. IX. A method for grading health care recommendations. Evidence-Based Medicine Working Group [published erratum appears in JAMA 1996 Apr 24;275(16):1232]", *JAMA: The Journal of the American Medical Association*, vol. 274, no. 22, pp. 1800-1804.

Hawe, P., Shiell, A., & Riley, T. 2004, "Complex interventions: how "out of control" can a randomised controlled trial be?", *BMJ*, vol. 328, no. 7455, pp. 1561-1563.

Hawthorne, K., Robles, Y., Cannings-John, R., & Edwards, A. G. K. 2008, "Culturally appropriate health education for type 2 diabetes mellitus in ethnic minority groups", *Cochrane Database of Systematic Reviews*, vol. 3, no. Issue 3. Art. No.: CD006424.DOI: 10.1002/14651858., pp. 1-354.

Heisler, M., Faul, J. D., Hayward, R. A., Langa, K. M., Blaum, C., & Weir, D. 2007, "Mechanisms for racial and ethnic disparities in glycemic control in middle-aged and older Americans in the health and retirement study", *Arch.Intern.Med*, vol. 167, no. 17, pp. 1853-1860.

Hoddinott, P., Britten, J., Prescott, G. J., Tappin, D., Ludbrook, A., & Godden, D. J. 2009, "Effectiveness of policy to provide breastfeeding groups (BIG) for pregnant and breastfeeding mothers in primary care: cluster randomised controlled trial", *BMJ*, vol. 338, p. a3026.

Hoddinott, P., Lee, A. J., & Pill, R. 2006, "Effectiveness of a breastfeeding peer coaching intervention in rural Scotland", *Birth*, vol. 33, no. 1, pp. 27-36.

Hoddinott, P. & Pill, R. 1999, "Qualitative study of decisions about infant feeding among women in east end of London", *BMJ*, vol. 318, no. 7175, pp. 30-34.

Hoddinott, P. & Pill, R. 2000, "A qualitative study of women's views about how health professionals communicate about infant feeding", *Health Expect.*, vol. 3, no. 4, pp. 224-233.

Hoddinott, P., Pill, R., & Chalmers, M. 2007, "Health professionals, implementation and outcomes: reflections on a complex intervention to improve breastfeeding rates in primary care", *Fam.Pract*, vol. 24, no. 1, pp. 84-91.

Hoddinott, P., Pill, R., & Hood, K. 2000, "Identifying which women will stop breast feeding before three months in primary care: a pragmatic study", *Br J Gen Pract*, vol. 50, no. 460, pp. 888-891.

Howie, J. G., Heaney, D. J., Maxwell, M., & Walker, J. J. 1998, "A comparison of a Patient Enablement Instrument (PEI) against two established satisfaction scales as an outcome measure of primary care consultations", *Family Practice*, vol. 15, no. 2, pp. 165-171.

Jordan, J. E. & Osborne, R. H. 2007, "Chronic disease self-management education programs: challenges ahead", *Med J Aust*, vol. 186, no. 2, pp. 84-87.

Khunti, K., Camosso-Stefinovic, J., Carey, M., Davies, M. J., & Stone, M. A. 2008, "Educational interventions for migrant South Asians with Type 2 diabetes: a systematic review", *Diabet.Med.*, vol. 25, no. 8, pp. 985-992.

Kleinmann, A. 1988, *The illness narratives: suffering, healing and the human condition.* Basic Books, New York.

Kreps, G. L. & Sparks, L. 2008, "Meeting the health literacy needs of immigrant populations", *Patient.Educ.Couns.*, vol. 71, no. 3, pp. 328-332.

Lave, J. & Wenger, E. 1991, *Situated Learning: Legitimate peripheral participation* Cambridge University Press, Cambridge.

Lindstrom, J., Peltonen, M., Eriksson, J. G., Aunola, S., Hamalainen, H., Ilanne-Parikka, P., Keinanen-Kiukaanniemi, S., Uusitupa, M., & Tuomilehto, J. 2008, "Determinants for the effectiveness of lifestyle intervention in the Finnish Diabetes Prevention Study", *Diabetes Care*.

Little, M., Jordens, C. F., Paul, K., Montgomery, K., & Philipson, B. 1998, "Liminality: a major category of the experience of cancer illness", *Social Science & Medicine*, vol. 47, no. 10, pp. 1485-1494.

Loveman, E., Frampton, G. K., & Clegg, A. J. 2008a, "The clinical effectiveness of diabetes education models for Type 2 diabetes: a systematic review", *Health Technol.Assess.*, vol. 12, no. 9, pp. 1-116, iii.

Loveman, E., Frampton, G. K., & Clegg, A. J. 2008b, "The clinical effectiveness of diabetes education models for Type 2 diabetes: a systematic review", *Health Technol.Assess.*, vol. 12, no. 9, pp. 1-116, iii.

Marmot, M. & Brunner, E. 2001, "Epidemiological applications of long-term stress in daily life", *Adv.Psychosom.Med*, vol. 22, pp. 80-90.

Mattingly, C. 1998, *Healing Dramas and Clinical Plots: The Narrative Structure of Experience* Cambridge University Press, New York.

McCormack, L. A., Williams-Piehota, P. A., Bann, C. M., Burton, J., Kamerow, D. B., Squire, C., Fisher, E., Brownson, C. A., & Glasgow, R. E. 2008, "Development and Validation of an Instrument to Measure Resources and Support for Chronic Illness Self-management: A Model Using Diabetes", *Diabetes Educ*, vol. 34, no. 4, pp. 707-718.

Millett, C., Saxena, S., Ng, A., Mainous, A., III, & Majeed, A. 2007, "Socio-economic status, ethnicity and diabetes management: an analysis of time trends using the health survey for England", *J Public Health (Oxf)*, vol. 29, no. 4, pp. 413-419.

Mishler, E. G. 1984, *The Discourse of Medicine: Dialectics of Medical Interviews.* Ablex, Norwood, N.J.

Mol, A. 2008, *The logic of care: health and the problem of patient choice* Routledge, London.

Newbould, J., Taylor, D., & Bury, M. 2006, "Lay-led self-management in chronic illness: a review of the evidence.", *Chronic Illness*, vol. 2, no. 4, pp. 249-261.

Newman, S., Steed, L., & Mulligan, K. 2004, "Self-management interventions for chronic illness", *Lancet*, vol. 364, no. 9444, pp. 1523-1537.

Nussbaum, M. 2001, *Upheavals of thought: The intelligence of emotions* Cambridge University Press, Cambridge.

Nutbeam, D. 2000, "Health literacy as a public health goal: a challenge for contemporary health education and communication strategies into the 21st century.", *Health Promotion International*, vol. 15, pp. 259-267.

Osborne, R. H., Elsworth, G. R., & Whitfield, K. 2007, "The Health Education Impact Questionnaire (heiQ): an outcomes and evaluation measure for patient

education and self-management interventions for people with chronic conditions", *Patient.Educ Couns.*, vol. 66, no. 2, pp. 192-201.

Osborne, R. H., Jordan, J. E., & Rogers, A. 2008, "A critical look at the role of self-management for people with arthritis and other chronic diseases", *Nat.Clin.Pract Rheumatol.*, vol. 4, no. 5, pp. 224-225.

Pawson, R. & Tilley, N. 1997, *Realistic evaluation.* Sage, London.

Polanyi, M. 1962, *The tacit dimension.* Anchor Day, New York.

Polanyi, M. 1958, *Personal knowledge: Towards a post-critical philosophy* University of Chicago Press, Chicago.

Putnam, R. D. 2000, *Bowling Alone. The collapse and revival of American community* Simon and Schuster, New York.

Rabi, D. M., Edwards, A. L., Southern, D. A., Svenson, L. W., Sargious, P. M., Norton, P., Larsen, E. T., & Ghali, W. A. 2006, "Association of socio-economic status with diabetes prevalence and utilization of diabetes care services", *BMC Health Serv Res*, vol. 6, p. 124.

Ricoeur, P. 1984, *Time and narrative, Volume 1* University of Chicago Press, Chicago.

Riessman, C. K. 2008, *Narrative Methods for the Human Sciences* Sage, Thousand Oaks, CA.

Ritchie, J. & Lewis, J. 2003, *Qualitative research practice* Sage, London.

Robb, N. & Greenhalgh, T. 2006, ""You have to cover up the words of the doctor": the mediation of trust in interpreted consultations in primary care", *J Health Organ Manag.*, vol. 20, pp. 434-455.

Rogers, A. 2009, "Advancing the Expert Patient", *Primary Health Care Research & Development*, vol. 10, pp. 167-176.

Schillinger, D., Grumbach, K., Piette, J., Wang, F., Osmond, D., Daher, C., Palacios, J., Sullivan, G. D., & Bindman, A. B. 2002, "Association of Health Literacy With Diabetes Outcomes", *JAMA: The Journal of the American Medical Association*, vol. 288, no. 4, pp. 475-482.

Snoek, F. J. 2002, "Breaking the barriers to optimal glycaemic control--what physicians need to know from patients' perspectives", *Int.J Clin.Pract Suppl* no. 129, pp. 80-84.

Sontag, S. 1979, *Illness as metaphor* Allen Lane, London.

Stevens, R. J., Kothari, V., Adler, A. I., & Stratton, I. M. 2001, "The UKPDS risk engine: a model for the risk of coronary heart disease in Type II diabetes (UKPDS 56)", *Clin.Sci.(Lond)*, vol. 101, no. 6, pp. 671-679.

Strauss, A. L. 1975, *Chronic Illness and the Quality of Life* Mosby, St Louis.

Tang, Y. H., Pang, S. M., Chan, M. F., Yeung, G. S., & Yeung, V. T. 2008, "Health literacy, complication awareness, and diabetic control in patients with type 2 diabetes mellitus", *J.Adv.Nurs.*, vol. 62, no. 1, pp. 74-83.

Thomas, C., Hypponen, E., & Power, C. 2007, "Diabetes risk in British adults in mid life: a national prevalence study of glycated haemoglobin", *Diabet.Med*, vol. 24, no. 3, pp. 317-321.

Trento, M., Passera, P., Borgo, E., Tomalino, M., Bajardi, M., Cavallo, F., & Porta, M. 2004, "A 5-year randomized controlled study of learning, problem solving ability, and quality of life modifications in people with type 2 diabetes managed by group care", *Diabetes Care*, vol. 27, no. 3, pp. 670-675.

Turner, V. 1980, "Social dramas and stories about them", *Critical Inquiry*, vol. 7, pp. 141-168.

Utz, S. W., Williams, I. C., Jones, R., Hinton, I., Alexander, G., Yan, G., Moore, C., Blankenship, J., Steeves, R., & Oliver, M. N. 2008, "Culturally tailored intervention for rural African Americans with type 2 diabetes", *Diabetes Educ.*, vol. 34, no. 5, pp. 854-865.

Vijan, S., Stuart, N. S., Fitzgerald, J. T., Ronis, D. L., Hayward, R. A., Slater, S., & Hofer, T. P. 2005, "Barriers to following dietary recommendations in Type 2 diabetes", *Diabet.Med*, vol. 22, no. 1, pp. 32-38.

von Goeler, D. S., Rosal, M. C., Ockene, J. K., Scavron, J., & De Torrijos, F. 2003, "Self-Management of Type 2 Diabetes: A Survey of Low-lncome Urban Puerto Ricans", *The Diabetes Educator*, vol. 29, no. 4, pp. 663-672.

Vygotsky, L. S. 1979, *Mind in Society: The development of higher mental processes* Harvard University Press, Cambridge, MA.

Vygotsky, L. S. 1986, *Thought and language. Original text 1934, translated by Eugenia Hanfmann and Gertrude Vakar.* MIT Press, Cambridge MA.

Wann, M. 1995, *Building Social Capital: Self Help in a Twenty-first Century Welfare State* Published by Institute for Public Policy Research, London.

Warsi, A., Wang, P. S., LaValley, M. P., Avorn, J., & Solomon, D. H. 2004, "Self-management education programs in chronic disease: a systematic review and methodological critique of the literature", *Arch.Intern.Med*, vol. 164, no. 15, pp. 1641-1649.

Wenger, E., McDermott, R., & Snyder, W. 2002, *Cultivating communities of practice: a guide to managing knowledge.* Harvard Business School Press, Boston, MA.

Willging, C. E., Helitzer, D., & Thompson, J. 2006, "`Sharing wisdom': Lessons learned during the development of a diabetes prevention intervention for urban American Indian women", *Evaluation and Program Planning*, vol. 29, no. 2, pp. 130-140.

Winter, R. 1986, "Fictional-critical writing: an approach to case study research by practitioners", *Cambridge Journal of Education*, vol. 3, pp. 175-182.

Zanchetta, M. S. & Poureslami, I. M. 2006, "Health literacy within the reality of immigrants' culture and language", *Can.J.Public Health*, vol. 97 Suppl 2, p. S26-S30.

Appendix 1 Results of thematic analysis

DIAGNOSIS OF DIABETES

Almost all groups began with each person giving a spontaneous account of when and how they were diagnosed, and how they felt about this

Most had experienced shock, fear and feelings of hopelessness, stigma and isolation

Many knew of others who had developed terrible complications and anticipated that they would too (e.g. in one group, every participant had a friend or family member who had had an amputation)

Some had 'known' they had diabetes because they had observed similar symptoms in a relative, but their GP had refused to test them

Some had concealed the diagnosis from relatives (even spouse or fiancé[e])

KNOWLEDGE OF DIABETES

Whilst many participants were knowledgeable about diabetes and its management, others were very ignorant, revealing (usually after a few sessions) a lack of basic understanding

Group input often clarified serious confusion in those with poor understanding (e.g. one participant had conflated 'hypo' and 'hyper' so whenever she detected raised blood glucose, she had a sweet biscuit)

Learning that you 'should' have an annual eye check prompted some participants to approach their GP and ask to be referred for one

A common area of ignorance was the nature of the link between diabetes and complications / co-morbidity (e.g. high blood pressure, cholesterol, eye problems)

Many participants admitted not understanding "numbers" (e.g. HbA1c, cholesterol levels, blood pressure readings); there was much discussion and clarification based on real examples

MANAGING DIABETES

When asked how they managed their diabetes, participants usually began by offering an 'ideal' approach but in later sessions admitted that they sometimes cut corners (e.g. many omitted their medication; one person gave himself a "holiday" from diet and exercise every weekend; several only tested their blood glucose when they knew it would be low)

Many did regular blood tests (up to three times a day) but did not understand or act on the result; others were "too scared" to do any tests. Group discussion appeared to prompt reflection on why the tests were being done and what particular values meant

Practicalities of when and how to do blood tests were discussed at length (e.g. one participant asked "when should I test, is it when the doctor says or when I want to?")

Fatalistic attitudes ("I'm going to die anyway so why bother doing the tests or following a healthy life?") drew strong criticism from the group, who generally saw great value in taking control over one's diabetes

An Imam was invited to teach a predominantly Muslim group on managing diabetes. He stressed the importance of 'looking after your body which God has given you' and not fasting recklessly if you are ill (e.g. shorter fasts in the summer months; giving money to the poor instead of fasting etc)

Family members sometimes attended the group to complain that their relative was "stubborn" (e.g. did not follow diet or take medication as directed), and [implicitly] sought the group's input in motivating their relative to co-operate with family-led controls

Managing diabetes was often done alongside multiple other burdens e.g. managing other long term conditions; helping with a sick relative; looking after children or grandchildren

DIET

Diet was seen as "the hardest thing to control"

There was much exchange of recipes and cooking tips (including for home remedies such as bitter melon [kerela], a very sour food that is seen as 'balancing' the effect of sweet food)

Much discussion and negotiation of what sort of food is culturally acceptable and whether it is all right to turn down particular foods in particular contexts

Recurring story of efforts to control weight without success; group discussions on this theme appeared to lead to better understanding of the need to identify 'hidden fats' and control portion size as well as reduce sugar and visible fat

Many stories on the difficulty of fitting in one's special diet with wider needs and tastes of the family

Some described 'covering' festival food with extra medication (e.g. "it's OK to have X; just take an extra tablet afterwards"), but this usually led to dissent within the group

Religious foods and menus were frequently discussed, but were not (as some initially thought) non-negotiable. On the contrary, many told stories of Imans who advised not fasting when ill or frail, and others of how Sikh 'holy food' [prasaad] given in the temple had recently become much healthier in composition

MEDICATION

"Forgetting" to take medication was one of the commonest themes raised in all groups. Numerous practical tips were exchanged – e.g.

- one man left a full glass of water near his tablets; if the water was untouched, he knew he had not taken the tablets yet

- a woman who had recently immigrated from Somalia (where she was a member of a nomadic tribe) said she had begun to think of her numerous medications "like a herd of cattle, and I remember each one as a different cow"

- various suggestions were offered to a woman who admits frequently "forgetting" to take her late-night insulin because sleepy at that time of day

Much practical advice was exchanged for preventing and treating hypos (e.g. "don't make a cup of tea when you think you're having a hypo"). Those telling stories of recurrent hypos were advised by others in the group to see the nurse or GP

Some facilitators encouraged people to reflect on why a particular hypo might have occurred, and in some cases a story of unaccustomed exercise or missed meal was drawn out

On hearing others' stories about how to take medication, some participants realised they were taking theirs incorrectly

Many stories about side effects of medication and how GPs tend to dismiss these

Almost universally, participants described fear and reluctance when advised to go onto insulin, and were reassured when they heard the stories of people who were already on insulin (group members typically 'sided' with the health professional rather than the narrator in these stories)

Reluctance to go onto insulin sometimes had concrete fears attached (e.g. if I had a hypo I wouldn't be able to care for my disabled/dependent relative), but group discussion allowed people to work through these 'what-ifs' and reconsider their decision

Most insulin treated participants had never adjusted their dose to take account of food or exercise, but learnt from others' stories that this was possible and how to go about it

Many described weight gain on insulin and discussions centred on how to avoid this

Some admitted taking herbal remedies and the value of these was discussed, with no consensus

Many tips shared on how to adjust dose / timing of medications for Ramadan and other fasting occasions

ACCESSING SERVICES AND MANAGING HEALTH PROFESSIONALS

Numerous stories were shared of the general format "I've told my GP about X and he does nothing, and does not explain"; these draw suggestions from the more articulate members of "how to insist"

Some described difficulty getting an appointment to see the GP (especially with the commonly used system of 'phone on day', which was hard for limited English speakers), and again practical suggestions were offered on how to manage receptionists and appointment clerks

Many GPs 'rationed' the number of needles and test strips prescribed; there was no solution offered but the problem was seen to be common to many

One woman told how she had always previously been sent an annual appointment for eye screening; this year she had been sent a letter inviting her to phone and book one. She was reluctant to phone as her English was limited, but the group suggested that she should phone up as instructed. She decided to ask her daughter to phone

Many participants were ignorant about interpreting and advocacy services; group members shared contact details of these

FAMILY AND SOCIAL SUPPORT

Most participants relied heavily on family and social networks; older women in particular relied on their daughters or daughters-in-law to administer insulin or oversee tablets

Despite a good GP and diabetes specialist nurse, one person says "no-one cares for me with my diabetes" (meaning she has no family or close friends to help her)

Family members appeared to play a major role in controlling diet, helping prepare suitable food and withholding certain foods from the member with diabetes

FOOT CARE

Podiatrist sessions were very popular, with numerous stories about own foot problems being used to initiate and illustrate discussion

Many participants had "burning feet", and some complained that the doctor or nurse did not care, they only insisted on tighter blood glucose control. Group members explained that tighter control was not an unrelated issue but was being suggested as a means of reducing the burning

Hands-on session on footwear very popular; illustrated by stories of unsuitable footwear (e.g. someone who broke an ankle in high heels)

EXERCISE

Few were initially interested in exercise but the minority of enthusiasts told stories of walking (up to ten miles a day) and modelled indoor exercises within the group

Some described lack of energy or inability to exercise (e.g. angina)

Group members exchanged details of exercise opportunities e.g. details of women-only swimming sessions or organised outdoor walks

Some people who preferred to exercise indoors described techniques for doing this e.g. one older couple walked back and forth across the living room for an hour after supper

Stories of hypos during exercise prompt facilitator to invite group to reflect on link between exercise and fall in blood glucose

Many groups initiate regular chair-based exercises as a 'warm up' to the sharing stories session

As participants become more confident in chair-based exercise, they begin to tease and encourage each other, e.g. "you can't do that properly, you are too fat"; "you are doing it all wrong, watch me"

Appendix 2 Points raised in the evaluation of the story-sharing groups

WHAT WOULD YOU TELL A FRIEND WITH DIABETES ABOUT THE GROUP?

The group has made me more aware / pay attention more / care more

The group has been enjoyable; I have made friends

We discuss problems and how to solve them

We learn from each other

We learn facts from you [health professionals] but we learn the meaning from one another

Come to the group to learn what questions to ask (mentioned in almost all groups)

We learn how to take our medication and what it is for

We don't always come to the group because we need to learn something but to hear others' experiences

Talking helped us learn about doing things

I can also help my husband / family / other relatives now

I learnt so many things and can still remember them

You care enough about us to arrange the group

It was very nice, we didn't think of dress, community, religion but found out instead that we all had the same problem

We can admit things to each other like eating sweets

WHAT HAS CHANGED IN YOUR LIFE AS A RESULT OF ATTENDING THE GROUP

My diet has changed (and family's diet); learnt new recipes

Put away my big plates and bought smaller ones

I walk more / exercise more

Was housebound but now I go out, have started prescription for exercise classes

My blood sugars are under control since coming to the group regularly

I take my medicines "properly"

I know how to inject my insulin

My mood has been better and I am much happier (described themselves as 'depressed' in an early group session)

I feel more confident and am telling others in my family / community how to manage their diabetes

After 35 years with diabetes I had begun not to care any more; the group has motivated me to care again

I have learnt so much from others in my own language, now I am motivated to learn English so I can communicate better

It is very easy to understand here, you can talk face to face, ask many questions

This [group] is gradual and slow and you can ask the same [question] again. With the GP everything is 'NO' – don't eat, don't do that, no you can't! [Everyone laughs and agrees]

"Its not only learning about diabetes, but building up my confidence AND learning English! I asked my daughter to make me an appointment at the GPs but she said, no, now you are going to the group do it yourself – so I did!. Now I am feeling so much better (confident) that I want to join evening classes in English. I want to come to the group forever. I am also walking more now, I don't use the car like before"

"We were 'de-stressed' coming here, we gained knowledge, know more and feel so refreshed when we get back home. The way in which we were treated was also very good. I hate attending appointments but loved coming here."

HOW SHOULD WE CHANGE THE GROUPS?

Continue them (participants were very disappointed that groups stopped after 12 sessions)

Make sure health professionals don't cancel at the last minute

IMPRESSIONS OF GROUP FACILITATORS (MOSTLY BILINGUAL HEALTH ADVOCATES)

Felt strongly that participants had gained a great deal from the group, especially consolidation of knowledge, making knowledge meaningful, overcoming social isolation and lack of confidence

Many participants had been reluctant at first, but those who attended at all (about two-thirds of those randomised) generally kept coming and became more positive about the group as they attended more sessions

Some examples of apparently life-changing transformation e.g. one woman who never had courage to do anything herself before coming to group: lived

here many years but never learnt English, now she has joined an English class and she is no longer dependent on her husband to drive her places.

Perception that some come to the group with terrible fears (e.g. relative who died young of diabetes) and overcome them

Group allows knowledge to be personalised and 'made sense of' in the group. People ask practical questions "can I still dig in my garden?", "can I still pull a trolley?"

There is a sense of collective responsibility for addressing the needs of the more vulnerable / less knowledgeable members (e.g. women in group offering support to a man recently widowed who had not yet learnt to cook or care for himself)

Practical sessions on blood testing greatly valued

"The lottery of randomisation was very hard" – many of those randomised to standard education were simply not interested as had had education sessions before

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