

Diabetes self-management education: acceptability of using trained lay educators

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ABSTRACT

Background The use of lay people to deliver education programmes for people with chronic conditions is a potential method of addressing healthcare staff capacity and increasing the cost efficiency of delivering education. This qualitative substudy is embedded within an equivalence trial (2008–2011 including development stage).

Objectives In the qualitative substudy, we aimed to elicit the views of key stakeholders (patients, educators) about using lay people to deliver education to people recently diagnosed with type 2 diabetes, alongside a healthcare professional educator with an equal role. In this way, we sought to explore perceptions about acceptability and also contribute to understanding the reasons underlying positive or negative quantitative findings from main trial.

Methods We conducted 27 telephone interviews with a purposive sample of patients, lay educators and healthcare professional educators involved in the main trial. Thematic analysis of transcribed data was underpinned by the constant comparative approach and structured using Framework methodology.

Results Overall, the data suggested that the use of lay educators was acceptable to educators and patients. Perceived difference in knowledge levels between lay and healthcare professional educators did not appear to have an impact on perceived acceptability or the effectiveness of the education received. Additional themes explored were related to peer status of educators and feasibility. Some concerns were raised about lay educators with diabetes, transferring personal issues and about the impact of healthcare professional time taken up by mentoring and supporting lay educators.

Conclusions Positive perceptions about the use of lay educators support the positive quantitative findings from the main trial. Acceptability is an important consideration in relation to implementation of the model of delivery studied. Concerns raised within the interviews should be considered in the design of training for lay educators.

Trial registration number ISRCTN 99350009.

INTRODUCTION

The management of type 2 diabetes is a challenge for healthcare providers worldwide. In the UK there are over 3 million people diagnosed with diabetes, a number expected to rise to five million by 2025.¹ Provision of structured self-management education programmes, as recommended by national and international guidelines,^{2–4} is one way to assist with managing this chronic condition. Programmes should be designed to promote patient empowerment, providing individuals with the necessary skills and knowledge to manage their condition on a day-to-day basis. In the UK,

programmes such as Diabetes Education and Self Management for Ongoing and Newly Diagnosed (DESMOND)⁵ and X-pert⁶ have been specifically designed for people with type 2 diabetes. They have demonstrated that structured self-management education can result in enhanced quality of life, quality of care and improved physical health of patients.^{5–6} In the UK, however, data have shown that in 2009–2010 only 10% of those diagnosed with diabetes in the previous 12 months received structured education.⁷ Reasons for limited provision are likely to include availability and capacity of healthcare professionals to deliver the programmes.

The use of lay people to deliver education programmes for people with chronic conditions is a potential method of addressing capacity and increasing the cost efficiency of delivering education.⁸ The Expert Patients Programme⁹ is a key lay-led initiative in the UK. The programme is an adapted version of the Chronic Disease Self Management Programme that was developed in the USA in the 1990s by Kate Lorig and colleagues. The programme is delivered by lay people who themselves have a chronic condition. A Cochrane systematic review of lay-led self-management programmes concluded that these initiatives led to short-term improvements in patients' confidence to manage their condition and their perceptions of their own health and also increased the amount of exercise undertaken.⁸ To our knowledge, however, there has previously been no programme in the UK where lay educators have had an equal status to that of healthcare professional educators. The aim of the DESMOND Lay Educator study (box 1) was to address this gap in the literature.

Quantitative findings from the trial have indicated equivalent positive changes in each study group,¹⁰ but it is important that evaluations also consider the question of the acceptability of the intervention being investigated, as this may have an impact on the feasibility of implementation. Information from previous studies is sparse in relation to the acceptability of using lay educators. Qualitative explorations can also be useful for helping to understand the reasons underlying positive or negative quantitative findings. The qualitative substudy reported in this paper, therefore, aimed to contribute to the overall DESMOND lay educator study by exploring the acceptability of using lay educators from the perspective of key stakeholders (patients, healthcare professional educators and lay educators) and also by exploring the reasons why the education sessions involving lay educators did or did not have an equivalent impact compared with sessions delivered using only healthcare professionals.

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Box 1 The Diabetes Education and Self Management for Ongoing and Newly Diagnosed (DESMOND) Lay Educator study¹⁰

Study design and timing: Non-randomised equivalence trial with a qualitative substudy, conducted between 2008 and 2011 (including development stage).

Setting: Recruitment for the trial was through general practices (primary care centres) in four areas across England and Scotland.

Intervention: Non-randomised participant allocation to a DESMOND course delivered in the standard format by two trained healthcare professional educators (control format) or by one formally recruited, trained lay educator and one professional educator (intervention format). Having diabetes was not a selection or exclusion criterion for recruitment of lay educators.

Participants: A total of 260 patient participants attended DESMOND education courses (n=42) delivered in either the control or the intervention format.

Eligibility: Patients aged ≥ 18 years who had been diagnosed in the previous 12 months with type 2 diabetes and were not on insulin.

Aims and quantitative outcome measures: To develop and test a format of delivery of diabetes self-management education by paired professional and lay educators. The primary outcome measure was change in illness coherence score (derived from the Diabetes Illness Perception Questionnaire-Revised) between baseline and 4 months after attending education sessions; secondary outcome measures included change in blood glucose control.

Results: When comparing changes in illness coherence scores between the intervention and control groups, there was no statistically significant difference (0.22 (95% CI -1.07 to 1.52), $p=0.74$). The 95% CI was within the predefined limits of equivalence, indicating that the impact of the education sessions had been equivalent in the two study groups in relation to the primary outcome measure. No statistically significant between-group differences were seen for changes in any of the biomedical outcomes, with equivalent reductions in blood pressure, HbA1c, cholesterol, triglycerides, weight, body mass index and waist circumference in the two groups.

Conclusions: Diabetes education delivered jointly by a trained lay person and a healthcare professional educator with the same educator role can provide equivalent patient benefits compared with education delivered by two healthcare professional educators.

METHODS**Design and sampling**

Qualitative data were collected using a series of semistructured telephone interviews. Patients and educators (lay and healthcare professional) from the intervention arm of the study (education sessions delivered by one healthcare professional and one lay educator) were invited to participate. Purposive sampling was used for all interviews to obtain data from a range of people in terms of the geographical location of study sites and also (for patients) age and gender and (for educators) lay or professional background. Data saturation was monitored to determine the final number of interviews.

Data collection

The conduct of the semistructured interviews was based on open questioning to elicit feedback and explore areas of interest. We aimed to explore patients' perceptions about the delivery skills and knowledge of the educators and the interaction between the educators; we were also interested in eliciting information about whether patients had been aware of the lay or professional status of the two educators delivering the session that they had attended. In the interviews with educators, we aimed to explore their experiences of working with their partner educator and their perceptions about the skills and knowledge of their partner. Topic guides were developed to ensure that these areas of interest were explored, but these guides were used flexibly in terms of allowing participants to raise and discuss any additional issues pertinent to them. The topic guides were modified during the process of data collection if new areas of interest became apparent.

All interviews were conducted by an experienced qualitative researcher (MS). They were conducted by telephone and lasted approximately 20–30 min. Consent was obtained prior to the interview and was recorded onto a digital voice recorder using a file that was separate from the interview itself; this audio file was retained as a record of consent. The interview recordings were transcribed verbatim, with the proviso that no names were identified in the transcripts. Interviews were conducted with 16 patients who had attended intervention group sessions, 6 healthcare professional educators and 5 lay educators (table 1). Preliminary review of the data at this point suggested that no new themes were emerging and that relevant issues had been adequately explored. In line with our sampling strategy, those interviewed included a range of patients and both types of educator, from each of the four sites that took part in the trial.

Analysis

Thematic analysis of interview data involved two researchers (PM and MS). It was informed by the constant comparative approach¹¹ and was structured by the use of Framework methodology.¹² This process involved initial review of transcripts to identify relevant themes, development of a coding framework, detailed coding, charting and, finally, detailed review of the charts to map and interpret the data. The latter stage included consideration of patterns and meanings across cases and within and between themes. Initially, the analysis of interviews with patients and educators was carried out separately but the charted data for the two categories of interviewees were subsequently compared for common and linked themes.

RESULTS

Overall, the data from the substudy suggested that education delivery involving one lay educator and one healthcare

Table 1 Participants interviewed

Patients (n=16)	
Male	11
Female	5
Study site 1	4
Study site 2	5
Study site 3	3
Study site 4	4
Educators (n=11)	
Lay	5
Healthcare professional	6

professional educator with interchangeable roles was acceptable to the patients, healthcare professional educators and lay educators interviewed. In addition to this broad finding from the interviews, three themes which were considered to be of particular interest and relevance were identified: differences in knowledge, peer status and feasibility. These three key themes form the main focus of this paper, as presented below.

Differences in knowledge

One of the key themes within the data was related to perceived difference in the depth of knowledge that educators had on diabetes. The majority of patients perceived the level of knowledge between the two educators to be equal.

They were both very good...even if anything did come up they weren't phased 'cos they had the confidence because they knew they had the knowledge, they weren't having to grapple for information. (Patient interview 13)

However, a few felt that there was a distinct difference between healthcare professional and lay educators.

One of them was clearly confident in her knowledge...the other educator was less so. (Patient interview 1)

Some healthcare professional educators also commented on lower levels of knowledge in lay educators.

...there are times when they need a bit of physiological knowledge and if you're a lay educator who comes from a completely different field they won't have it. (Healthcare professional interview 1)

Detailed review of the charted data suggested, however, that perceptions about differences in knowledge levels had little impact on views about the acceptability of using lay educators. The majority of the participants were positive about the use of lay people as educators and believed that knowledge and confidence are something that develop with more practice and time.

Perceived differences in knowledge levels between lay and professional educators also appeared to have a low impact on the effectiveness of the education as suggested by reported behaviour change. Whether they had observed differences in the knowledge levels of the two educators, some patients described actively making changes since attending DESMOND, for example, increasing physical activity and making dietary changes, specifically a reduction in sugary and fatty foods.

it's made me think much more clearly about the foods I eat ... I'm now cutting things like biscuits that have a high sugar content. (Patient interview 1)

As a result of making lifestyle changes, three people reported losing weight and another reported reducing their medication and improving their blood glucose control.

Peer status

Another theme that emerged from the data, relevant to the acceptability of using lay educators, was peer status. Having diabetes was not a selection criterion for the recruitment of lay educators, but some of those recruited did have personal or family experience of the condition. In the patient interviews, peer status (lay educators having diabetes themselves) was seen as a positive attribute. They felt that the lay educator could empathise with them due to their own experience of living with the condition. One participant specifically described feeling comfortable asking the lay educator with diabetes questions, as they felt that the response obtained would be informed by

personal experience, while the healthcare professional was described as having the medical knowledge but no personal insight.

She [lay educator with diabetes] did know what she was talking about and she did know the pitfalls and what people would be facing, whereas the professional, you know the nurse, dealt with it from a professional point of view all the time but not from personally involved. (Patient interview 7)

I would think one of the advantages would be that...if the lay person is diabetic themselves they are speaking from personal experience. (Patient interview 14)

Lay educators with diabetes described how their peer status was a motivating factor that made their role as educators highly acceptable to themselves. They also felt that patients could benefit from the insight and empathy provided by an educator with diabetes.

I think sometimes I'm more empathetic to the patients because being a diabetic you could understand where they were coming from...more so I think that the professionals, I think sometimes they just got a fixed way of how things should be whereas if you're a diabetic you see it from their perspective. (Lay educator interview 4)

Healthcare professionals' views about peer status in lay educators were mixed, suggesting that this was something that could either add to or detract from their perceptions about the acceptability of delivering education with lay educator partners. One interviewee suggested, for example, that there could be benefits in terms of knowledge that was coming from a different perspective. Based on their experience of working with a lay educator with diabetes, however, they also felt that, if lay educators drew on their personal experience of diabetes, this could lead to personal issues being transferred.

I mean I think the advantage is they had something else to contribute from...coming from another point of view...but the disadvantages would be about... the lay educator transferring her personal issues in the group. (Healthcare professional interview 5)

Feasibility

The feasibility of using lay educators was another common theme identified during analysis. The majority of the patients, healthcare professional educators and lay educators suggested that having lay educators would be a benefit for the healthcare service. They felt that it would free up healthcare professionals' time, possibly be cost effective and provide a potential means of increasing the pool of educators to deliver structured education to the ever increasing numbers of patients with diabetes.

...the NHS is under such a strain...to have sufficient professionals to cover people that are coming into hospitals, going to doctors' surgeries etc, that if they can be freed up to continue doing the work that's necessary within those establishments, I think it's all to the good to be able to use lay people. (Patient interview 12)

...if that means that we're able to offer DESMOND you know to people and you know at the moment we're only offering erm... the newly diagnosed model er...with the use of lay educators we're hopefully gonna be able to introduce the foundation module [for people with established type 2 diabetes]... (Healthcare professional interview 4)

...if there's a cost advantage then almost it becomes it's...if the system is being starved of money and that is a cheaper way then you know it's gotta be the way forward. (Lay educator interview 1)

However, one healthcare professional educator was concerned about the amount of time that healthcare professionals might need to spend with lay educators to support them and provide mentorship.

...it was down to me and with everything else going on in my role it was quite difficult to...to set time aside. (HCP interview 5)

DISCUSSION

Summary of main findings

Our qualitative findings support the positive quantitative findings from the DESMOND Lay Educator study,¹⁰ which indicated that patients can derive equivalent benefits from education sessions involving one lay educator and one healthcare professional educator, compared with sessions delivered by two healthcare professional educators (box 1). The findings from our interviews with a range of stakeholders highlighted some concerns, but we identified positive overall perceptions regarding the acceptability of using lay educators. Detailed exploration of the data suggested that concerns about lack of knowledge in lay educators did not appear to influence either the effectiveness or the acceptability of using lay people. Two additional themes regarding peer status and feasibility helped to explain positive perceptions about the use of lay educators.

Strengths and limitations

The DESMOND Lay Educator study has filled a gap in the literature, providing both quantitative and qualitative findings. As discussed in our previous paper,¹⁰ we are aware of no previous study that has explored the use of lay people to deliver diabetes structured group education alongside a healthcare professional educator, with each type of educator having an equal, interchangeable role.

For the qualitative study described in this paper, we used purposive sampling, which included collecting data from three stakeholder groups (patients, healthcare professional educators and lay educators) from a range of geographical locations; this strengthens our findings by providing an insight from different perspectives.

The DESMOND Lay Educator study was designed to include two sites where the intervention would be delivered to people from South Asian backgrounds; however, the two sites were withdrawn during the development phase of the project, prior to the start of the main trial. Reasons for withdrawal were linked mainly to levels of competency achieved by the lay educators and competing commitments. This meant that we were unable to include interviews with stakeholders from these two sites, where specific issues relating to delivering education to people from ethnic minority background might have been explored.

Comparisons with previous literature

Concerns about limited diabetes knowledge in lay people involved in diabetes education and care have been raised by previous authors. In a study by Heisler *et al.*,¹³ participants attending a successful community health worker programme expressed concerns about the depth of diabetes knowledge possessed by family health advocates. In their paper considering methods of implementation of the community health worker model within diabetes programmes, Cherrington *et al.*¹⁴ reported that project managers of a range of programmes had expressed concerns about non-professionals giving misguided and inaccurate information. In a successful diabetes education programme delivered

in the UK by lay people, a healthcare professional was present to ensure that incorrect information was not given to patients.¹⁵ Although the question of knowledge limitations was raised in our interviews, overall this was not viewed as an important problem by patients and educators. This may be partly explained by the fact that, in the DESMOND programme, the educator is not meant to be the expert. Their role is rather to empower patients to work things out for themselves and identify ways of increasing their own knowledge. In addition, the lay educators in our study had undergone an intensive training programme, including opportunities to practise delivering sessions and accreditation based on quality assessment.

In our study, the role of those educators who had personal experience of diabetes differed from the peer support role (see online supplementary education sessions) described by other authors including Simmons *et al.*¹⁶ Peer status has, however, been previously highlighted as a positive attribute in education provision. In a qualitative study relating to education for people at risk of diabetes, Scarpello *et al.*,¹⁷ for example, described how patients valued the trainers' experience of living with diabetes and their knowledge of the practical ways in which this could be managed. Although our findings support this view, they have also highlighted a potential disadvantage in terms of educators with diabetes finding it difficult to avoid transferring their personal concerns to the people receiving education.

Implications for policy, practice and future research

The study has indicated that using lay educators to deliver DESMOND would be acceptable to those delivering and receiving education. Alongside our previously reported quantitative findings,¹⁰ this suggests that the use of lay educators paired with healthcare professional educators would be a feasible method of increasing capacity to deliver education to the growing number of people with type 2 diabetes. Further investigation may be warranted regarding specific issues relating to recruitment, training and retention of lay people to deliver diabetes education to people from ethnic minority communities, using the same model of paired lay and professional educators. One of the reasons for pairing lay educators with health professional educators in this study was related to risk management and the question of using two lay educators to deliver DESMOND would require additional evaluation.

Our findings have also drawn attention to some potential issues that could be addressed in the design of recruitment and training programmes for lay educators and healthcare professionals working alongside them. Our findings suggest that it may be useful to consider peer status as a positive (though not essential) attribute during recruitment of lay educators, but potential problems regarding transferral of personal issues should be explored and addressed during training. The design of training and mentoring programmes for lay educators should also recognise and take account of the amount of healthcare professional time involved in supporting lay educators. Building on the experience of, and findings from, the DESMOND Lay Educator study, the DESMOND programme currently requires that all lay people wishing to become lay educators should first identify a mentor who is willing to provide them with support and mentorship until they have been accredited.

Finally, we believe that the data provided by the qualitative substudy reported in this paper has both supported and complemented the quantitative data from the main trial, thus emphasising the benefits of including qualitative methods within the overall design of future trials.

Main messages

- ▶ Using trained lay educators to deliver self-management education for people with chronic diseases such as type 2 diabetes would be acceptable to patients.
- ▶ Using lay educators would also be acceptable to lay and healthcare professional educators.
- ▶ The use of lay educators would be a feasible method of increasing capacity to deliver self-management education.
- ▶ The findings from the qualitative substudy have supported and complemented the quantitative results of the main trial.

Current research questions

- ▶ In what ways does peer status influence chronic disease education delivery?
- ▶ Can acceptable and effective self-management education be delivered by lay educators to people from non-English-speaking ethnic minority groups?
- ▶ How acceptable would a lay educator be if delivering self-management education individually or paired with another lay educator?

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Competing interests None.

Patient consent Obtained

Ethics approval The study was approved by the Leicestershire, Northamptonshire & Rutland Research Ethics Committee 1 (09/H0406/87).

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