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# A qualitative assessment of using lay trainers with type 2 diabetes in an intervention programme for people at risk of type 2 diabetes

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#### **Abstract**

**Objective:** More knowledge is needed on the impact of expert patients within health intervention programmes. The University of East Anglia Impaired Fasting Glucose (UEA-IFG) feasibility programme was a structured dietary and exercise intervention to reduce the risk of type 2 diabetes mellitus (T2DM) in susceptible individuals. Lay volunteers with T2DM (T2 trainers) were recruited to support participants in adopting healthier lifestyles. This study aimed to explore the acceptability, perceived effectiveness and sustainability of lay trainers within the programme.

**Design:** A qualitative focus group study.

**Setting:** A clinical research unit in Norwich, United Kingdom (UK).

**Method:** Focus groups were conducted with: (1) T2 trainers (n = 15); (2) programme participants who had received their support (n = 11); and (3) salaried staff facilitators who had worked alongside the T2 trainers (n = 3). Framework analysis was applied to identify the different experiences of the lay trainer role. **Results:** All groups perceived advantages for peer support, particularly in sharing the day-to-day experiences of living with T2DM. However, staff facilitators raised the importance of role boundaries, emphasizing that T2 trainers should not provide medical advice. Acceptability of T2 trainers was enhanced by contacting participants at a convenient time and before substantial lifestyle changes had been made.

**Conclusion:** Lay trainers were seen as a complementary method to motivate individuals to reduce their risks of T2DM. A less prescriptive approach needs to be adopted to enable full integration of lay trainers, allowing them a greater level of contribution. To sustain effective use of lay trainers, health professionals need to work alongside volunteers and be trained to encourage peer involvement.

#### **Keywords**

diabetes, lay trainers, prevention programme, qualitative

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#### Introduction

The prevalence of type 2 diabetes (T2DM) is escalating worldwide and, consequently, there is a growing pressure on healthcare resources and an emphasis on patient self-care for this chronic condition. Prior to development of T2DM, patients often pass through a stage of impaired glucose regulation or 'pre diabetes', and there is strong clinical evidence that, in these high-risk individuals, lifestyle interventions are effective in delaying the development of T2DM. However, these interventions are affordable only if implemented in group settings and with a financially-sustainable number of health professionals. With the launch of the National Health Service (NHS) Expert Patient Programme, and an increasing attention to lay-led programmes, a logical extension is to use volunteer patients with diabetes to deliver education for T2DM patients and those at risk of the condition. Peer-led intervention programmes may improve management of T2DM and enhance patient self-efficacy, an important predictor of successful behaviour modification. Peers with established T2DM share common experiences with those at risk of the condition and are thus well positioned to encourage positive lifestyle practices.

Knowledge of the impact of expert patients in the field of T2DM, whilst growing, remains under-developed. Baksi and colleagues compared the effectiveness of expert patients with staff trained in the provision of self-management advice for diabetes, and concluded expert patients were just as effective in this role. Qualitative assessment of peer-delivered support for diabetes management has shown that patients are generally positive towards this, finding such support to be a useful addition to standard care. More research is required in this field and, in particular, in the area of T2DM prevention, for those at risk of the condition.

We proposed to use lay trainer volunteers with T2DM (known as T2trainers) within the University of East Anglia Impaired Fasting Glucose (UEA-IFG) feasibility programme, which aimed to reduce the risk of T2DM in individuals at high risk of the condition. This sub-study reports on the use of focus groups to assess the acceptability, perceived effectiveness and sustainability of the T2 trainers.

#### **Methods**

#### Study setting

The role of T2 trainers was to support participants in making healthier lifestyle changes. Participants with established impaired fasting glucose (IFG) or T2DM attended four 'core' dietary and exercise education sessions and subsequently a series of group 'after-core' discussions, facilitated by salaried staff. To encourage participants to reach their lifestyle goals, T2 trainers made 20-minute telephone calls to individual participants at three-monthly intervals, and supported participant 'after-core' sessions on an ad-hoc basis.

Eligible T2 trainers were aged between 18 and 70 years, with a diagnosis of T2DM for at least two years. Selection for their voluntary role was made through a pre-recruitment questionnaire and an informal interview. T2 trainers received seven two-hour education sessions covering nutrition, exercise and practical training in preparation for undertaking motivational telephone calls. All education sessions were based on information used by the Diabetes Prevention Programme, which is freely available in the public domain.<sup>4</sup> Material was tailored to a UK setting and established models of behavioural change were incorporated, principally Bandura's social cognitive theory and elements from empowerment theory. <sup>12,16,17</sup> T2 trainers were recruited, trained and supported throughout almost exclusively by a full-time salaried member of staff, the T2 trainer coordinator.

Ethical approval for the study was obtained from Essex 1 Research Ethics Committee (reference: 08/H0301/102) and East Norfolk and Waveney Research Governance Committee (reference: 2008EC06L).

#### Focus group setting and sampling

To explore the acceptability and perceived effectiveness of T2 trainers involved in the programme, focus groups were conducted with three different participant groupings:

- 1. T2 trainers: all available lay trainers were approached to participate in one of two focus group sessions. Of 24 invited, 15 took part.
- Programme participants: participants were purposively selected for one of two focus groups
  to obtain a representative sample of age, gender and length of study participation. From 25
  invited, 11 took part.
- 3. Staff facilitators: all three staff members delivering the intervention programme were invited, and took part in a single focus group.

#### Focus group sessions and analysis

Focus groups were facilitated by the third author, an experienced qualitative researcher with no previous association with the UEA-IFG programme. The groups were held approximately mid-way through the programme at a time when T2 trainers had some initial experience of supporting participants. Structured prompts were derived from a framework of questions for the programme and were tailored for each participant grouping. Major prompts focused on the T2 trainers': (1) training and support; (2) telephone support to participants; (3) session support to participants; and (4) sustainability of their overall role and expectations for the future. Focus groups (mean duration 58 minutes) were transcribed verbatim and analyzed using Nvivo (version 8). Transcripts were read and annotated by the first four authors and were coded in full by the third author according to the major prompts derived from the programme framework. The T2 trainer coordinator was involved in reviewing data coding and was therefore trained to act reflexively by acknowledging her key role in supporting T2 trainers. All analyzers met to compare and contrast data to validate findings.

#### Results

#### Theme 1: Role and role conflict

Programme participants perceived the T2 trainer role to be effective, and valued their experience of living with diabetes and their knowledge of the practical ways in which this could be managed. Likewise, T2 trainers described how their desire to use their experience to aid others with a similar condition had acted as a primary motivator to join the programme. An opportunity to enhance their personal knowledge of healthier living was identified as a secondary factor:

Respondent (R)1: I'd like to put something back and of course, there is the selfish side of it as well, by knowing more about it I'm in a better position to help myself. (T2 trainer, group 2)

T2 trainers described their overall role as one of support for programme participants. Staff facilitators were in agreement, although raised the importance of role boundaries. There was a sense of

compartmentalization and uncertainty as to the dynamics of the T2 trainer role and how to optimize links and communication between the different parties. Staff facilitators were concerned about the level of time commitment which could reasonably be expected from the T2 trainer volunteers, and emphasized that, in line with the programme objectives, specialist health or medical advice should not be given by T2 trainers. Conversely, T2 trainers were keen for greater interaction with participants and believed they could offer more advice, based on a common sense approach. Conflicts of opinion as to the specific role and use of T2 trainers were common themes:

- R1: I would say there is a role for them but it very much depends on the individual. (Staff facilitator)
- R3: It's a professional divide really isn't it . . . we're employed in our role to do what we do whereas the type 2 trainers have volunteered and it's their personal choice to do it. (Staff facilitator)

#### Theme 2:Training and mentoring

T2 trainers perceived their training programme to be informative and effective, empowering them with the necessary skills for their role. Descriptions of particularly enjoyable and memorable aspects of the training were put forward:

R8: We did a game: which of these things do you think has got the most fat in it. And we actually got up and organized it and that was the thing that made the most impression on me and I think that is an excellent way of imparting information. (T2 trainer, group 2)

Programme participants and staff facilitators shared the desire to learn more about the volunteer-training programme, and this was related to improved role integration and communication with T2 trainers:

R2: I think it would probably be good to, on both sides, for them to meet the four of us as a team and get to know who we are as a team and have an opportunity to ask us questions. (Staff facilitator)

All three participant groups were in agreement that the mentorship provided to T2 trainers, primarily from the T2 trainer coordinator, was highly supportive and acted to enhance motivation and interest in the programme.

#### Theme 3:Telephone support

After completion of their training, T2 trainers described their enthusiasm to start telephone calls to support programme participants. They expressed a need for a greater frequency of calls and a shorter interval between the start of training and support:

R3: When we are trying to do relationship building and be, sort of a mentor type role, you can't do that out of nowhere, you have to build up that relationship. (T2 trainer, group 1)

Telephone support was in the early stages and T2 trainers expressed positive opinions of the limited calls they had made, with confidence in their abilities improving with time. It was felt that, for the majority of programme participants, the telephone support aided their transition to a healthier lifestyle:

R2: ... pose some questions that they wouldn't possibly want to ask, or be too frightened to ask. (T2 trainer, group 2)

R10: My first contact was a bit monosyllabic shall we say, you know, yes, no, etcetera, but after we, we tried you know probing for questions or asking them questions to get something, you know, back . . . I had a client, I could have been there for 24 hours and we would be still talking! (T2 trainer, group 2)

Many T2 trainers noted that the support that they could provide was dependent upon the individual characteristics of the programme participants and the stage that they had reached in their lifestyle changes:

R8: They've done what they've been asked to do, they're getting the exercise, they are losing weight on the diet, and there is very little left for me to say to them except to keep up with the positive reinforcement. (T2 trainer, group 2)

Programme participants largely perceived the calls to be effective in aiding their lifestyle changes. However, some participants noted that the calls were not always received at a convenient time:

R9: I thought we would have a call probably about once a month or something, because when the type 2 trainer phoned me I was on a roll, I was losing weight . . . but after a time you felt that you needed someone there to boost you a bit. (Programme participant, group 1)

Staff facilitators expressed mixed feedback they had received from participants on the use of the telephone calls and raised concerns regarding areas of responsibility:

R1: We are setting targets and giving advice to our participants whereas the type 2 trainers are not meant to be, definitely not setting targets. (Staff facilitator)

#### Theme 4: Education session support

The ad-hoc involvement of T2 trainers in evening 'after-core' education sessions was considered to reinforce telephone mentoring on a limited basis, with the main advantage described as an ability to put participants at their ease. As the intervention progressed, staff facilitators described how they had attempted to evolve mechanisms for ensuring the T2 trainers had an established and beneficial role within the 'after-core' education sessions. However, there was no clear consensus from staff or from programme participants concerning the value of T2 trainers in this particular role:

- R1: If you have a group that's quite difficult to get going it is really helpful to have a type 2 trainer there ... they will contribute when everyone else is silent and hopefully get the ball rolling again. (Staff facilitator)
- R2: Their need to get something from this experience can spill over and you find yourself in a situation where you're almost dealing with their issue in the group rather than the participant's issue. (Staff facilitator)

T2 trainers were in agreement with staff facilitators that their main role in the 'after-core' sessions lay in putting participants at their ease and contributing their personal experience of living with T2DM. Some T2 trainers had found this role easier than others:

R10: I have done three after-core sessions and I felt the first one, I possibly thought well what am I doing here because I didn't really contribute a lot but then on the second and third ones I have found them . . . very informative to the participant and they were all also very informative to me. (T2 trainer, group 1)

#### Theme 5: Role sustainability

Overall, programme participants and staff facilitators described the T2 trainer role to be beneficial and important to sustain:

- R3: What they bring to the table is their own life experience because they have something that none of us have which is type 2 diabetes which is knowledge that they can share with the participants. (Staff facilitator)
- R3: Very encouraging, very upbeat, very positive that it [type 2 diabetes] wasn't a disaster that it can be managed and you can have a perfectly fit and healthy life. (Programme participant, group 1)

T2 trainers expressed strong support for the UEA-IFG programme and wanted to be involved more in the future, fully utilizing their newly-developed mentoring skills:

R3: I really would like to see the study go forward and feel as though I can get more involved in it really. (T2 trainer, group 1)

All participants believed the T2 trainer role could be further refined to maximize their effectiveness. It was recommended that telephone support be started earlier and be delivered more frequently throughout the programme. An improved integration with other programme personnel was raised as a key factor to their future success. Specifically, enabling an opportunity for programme participants and staff facilitators to meet T2 trainers prior to the start of their involvement was felt to be of benefit. Further to the piloting of T2 trainer attendance within participant sessions, building this aspect formally into their training package was considered important.

#### **Discussion**

This study explored the acceptability and perceived effectiveness of volunteer lay trainers within a lifestyle intervention programme for people at risk of T2DM. Common threads identified were related to advantages in sharing practical experiences of managing diabetes, and to role differences in comparison to salaried professionals and boundaries of medical and health advice provided.

The principal advantage of using lay trainers was their ability to communicate methods of coping with T2DM in a way that participants could readily relate to. Patients reportedly place a high value in those who have diabetes who can provide reassurance through commonalities in experience and who can provide information relevant to practical living. 10,11,15,20 Given only standard care by health professionals, the ability for patients to undertake complex lifestyle changes may be reduced through 'professional domination' and limitations in participants' medical knowledge. 13,21 Lay trainers have the potential to bridge this cultural gap between patients and professionals.

For T2 trainers, motivators for participation were to support others with a similar condition, improve their *own* understanding of diabetes and be in contact with individuals sharing an interest in the condition. Others have reported that lay trainers find benefits of improved knowledge, greater social support and an increased ability to manage their own diabetes. <sup>11, 13, 15</sup> T2 trainers were reportedly empowered by their training and became progressively confident in their mentoring abilities

over time. The literature on appropriateness of training for lay mentors is relatively underdeveloped. Offering a short course with ongoing support and the opportunity for further learning, is an important factor to consider for ensuring continued motivation and retention within the role, 9, 22, 23 as reinforced by findings in this study.

Telephone-based peer support offers the potential for patient contact at relatively low cost.<sup>24</sup> However, this feasibility study identified minor negatives which would need to be addressed to ensure long-term effectiveness of this type of assistance. We concur with Dale et al.<sup>11</sup> in finding some difficulties in establishing a convenient time for telephone calls and in the reluctance of some individuals, who had already made significant lifestyle changes, to accept support. As highlighted through piloting the involvement of T2 trainers within participant sessions, using telephone support in conjunction with face-to-face contact, or other methodologies such as internet support, is likely to optimize benefits.<sup>24</sup> Ensuring flexibility in the methodology of approach, and appropriate timing and targeting of support to participants, are important factors to consider when establishing peer-mentored programmes.

Staff and participants interviewed expressed concern for the time commitment which could reasonably be expected from volunteers. However, this was not identified as a drawback by the T2 trainers involved, who in fact, wanted a greater level of involvement. The early influential work of Arnstein<sup>25</sup> highlights the benefits of providing those usually limited from decision making with the mechanisms to exert an influence, thus improving group productivity. Whilst the benefit of improved integration with T2 trainers was echoed by programme participants and staff facilitators, concerns involving how to negotiate boundaries of medical and health advice and the best way to complement the role of salaried professionals were raised. The use of lay trainers within the NHS is a relatively new concept and their relationship to professionals is ill-defined and an area of contention.<sup>26</sup> As a feasibility programme, the role of the T2 trainer was being established for the first time and these findings may have differed if the period of involvement had been longer. Indeed, other research demonstrates trust between professionals and lay trainers may improve with greater interaction time. <sup>10, 27</sup> This research highlights the need for such sensitivities to be addressed to provide appropriate participant care, whilst encouraging full peer involvement. Any programme involving lay trainers would need to incorporate a standardized training approach, and ensure professional boundaries were clearly defined, to enable health professionals to work alongside lay trainers, enabling their supervision and continued support.

As a feasibility programme, the sample size was small and recruited from one area of the UK. Nonetheless, the homogeneity of responses highlights generic issues which advance findings from previous studies. Thus it is likely the findings have general transferability and can inform the field of lay trainer support in early diabetes prevention.

The strength of lay trainer support lies within their ability to motivate people to utilize health messages in day-to-day living, and the minimal costs in comparison to salaried staff.<sup>26</sup> This research has demonstrated that lay trainer volunteers with a diagnosis of T2DM are perceived to be an effective and acceptable complementary method to motivate and empower individuals to make complex lifestyle modifications and reduce their risks of T2DM development. Greater integration of lay trainers, and allowing them a high level of programme involvement, are key factors likely to enhance their success.

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