Title: "And now for the good news..." the impact of negative and positive messages in self-management education for people with Type 2 diabetes: a qualitative study in an ethnically diverse population.

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Abstract

Objectives: To explore the impact of DESMOND Foundation education, particularly from interviewees' narratives regarding recall of good and bad news messages and behaviour changes.

Methods: In-depth, semi-structured interviews were conducted with a purposive sample

(n=19) of people who had attended education sessions as part of a randomised controlled trial in two UK sites with ethnically diverse populations. Data collection and analysis were informed by the constant comparative approach and facilitated through charting.

Results: Findings were similar in people from different ethnic backgrounds. Exploration of levels of recall of the sessions suggested that this was variable and sometimes very limited, but that interviewees had all assimilated some relevant learning. Key themes emerged relating to the way in which interviewees recalled and had been influenced by positive (good news) and negative (bad news) messages within the education sessions, including biomedical explanations. Both types of message appeared to have an important role in terms of motivation to change behaviour, but a notable observation was that none of the interviewees recalled receiving bad news messages when diagnosed.

Discussion: Our findings have highlighted the importance of providing and combining both negative and positive messages within education designed to promote self-management behaviour change.

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Key words:

Type 2 diabetes, structured education, self-management, qualitative research.

Introduction

Type 2 diabetes mellitus (T2DM) is a serious progressive chronic illness with potential associated complications including renal, heart and eye disease. It has been estimated that the global burden of all types of diabetes was almost 300 million adults in 2010, with a projected rise to over 400 million in 2030. [1] Over 3 million people in the UK are affected by diabetes, with Type 2 being by far the most common. [2] Despite advances in pharmacological interventions, prevention of complications in T2DM remains a challenge because of the importance of patient engagement in their own care, for example, in relation to diet and lifestyle modification, adherence to prescribed medication and, for some people, self-monitoring of blood glucose. This critical role for patients is known as self-management. Education that equips people with information and skills to actively self-manage their T2DM is therefore promoted as key to effective care. In the UK, for example, national guidance recommends structured self-management education. [3,4] Moreover, there are recommended standards for such structured education programmes. [5] Evidence indicates that structured education is cost-effective and can lead to improved biomedical and psychological outcomes. [6-11].

DESMOND (Diabetes Education and Self Management for Ongoing and Newly Diagnosed) is a programme of group-based structured patient education modules and related educator training that meets national standards and is a widely adopted programme in UK primary care. [6] It is supported by culturally relevant resources [12] and delivered by trained educators; interpreters provide facilitation where educators with relevant language skills are not available. This is pertinent to the UK population, within which people of South Asian origin have a particularly high prevalence of T2DM. [13,14] The DESMOND 'Foundation' programme is a version of the DESMOND Newly Diagnosed programme adapted to

specifically meet the needs of people with *established* T2DM (a duration of between 12 months and ten years).

The experience of living with T2DM has been the focus of many qualitative studies, and is widely recognised as being an issue of balance – between managing the condition and retaining as normal a life as possible in order to maintain well-being (for example, [15]).

Awareness of the increasing prominence of, and need for, self-management has been demonstrated in the narratives of people with T2DM, but is set against feelings of the weight of responsibility, and the need for structural requirements (services) to facilitate this. [16] Studies of the provision and receipt of services to support self-management have highlighted the impact on roles and relationships in the clinical encounter, [17] the differing challenges, barriers and needs of self-management (for example between genders - 18), and the influence of people's social, economic and cultural resources on their health capabilities to engage in, for example, the dietary management required. [19]

A smaller number of studies have explored participants' experiences of T2DM self-management education programmes. A qualitative study of people who attended the DESMOND Newly Diagnosed education sessions found mixed views of the format of the group-based education sessions, and the level and amount of information provided/learnt.

[20] Other studies have highlighted key types of knowledge that participants must learn on such programmes in order to initiate and maintain behaviour change. [21] A qualitative synthesis demonstrated the importance of fostering participants' sense of ownership in their diabetes management [22]. Less is known, however, about the impact of the educational messages and motivational techniques in self-management education sessions (such as DESMOND) and how they impact on different individuals.

The curriculum and activities in the DESMOND programme are underpinned by a set of principles and psychological theories. [23] One overarching principle is the concept of balancing 'bad news' and 'good news' which suggests that in order to motivate people to become active self-managers, they must be convinced of the progressive nature of the condition, including the threat of potential complications (the bad news), but simultaneously reassured that by improving their self-efficacy it is possible to make realistic and achievable behaviour changes that can have a positive impact in terms of delaying or preventing complications (the good news). This principle is informed by Leventhal's Common Sense Theory [24,25] which describes five core components that contribute to illness perceptions: identity, consequences, cause, control and timelines, of which consequences and timelines relate to the bad news about diabetes and control to the good news (see Box 2 for more details). Previous research has acknowledged the complexity of striking a balance between giving people with T2DM sufficient 'bad news' information about the risks and consequences of their condition to encourage self-management without provoking adverse psychological impact. [26] A particular challenge for T2DM education programmes is conveying knowledge about this bad news to participants who may be largely asymptomatic, depending on duration and progression. [21,27,28]

In the current paper, we aim to explore the impact of DESMOND on people's understandings and behaviour. To do this, we explore interviewees' narratives about what they recalled learning from the DESMOND Foundation sessions generally and whether and how their behaviour had changed. More specifically, we focus on their recall and understanding of motivation based on bad news and good news.

Methods

Setting

The DESMOND Foundation study is a multi-site cluster-randomised controlled trial testing the efficacy of the DESMOND Foundation programme in primary care in two ethnically diverse UK settings (Leicester and Birmingham). Participants in practices (primary care centres) randomised to the intervention arm attended the DESMOND Foundation programme. Three different formats (relating to language needs) were offered. Participants randomised to the control group received standard routine care for their condition at their general practice; this may have included being offered education (excluding DESMOND Foundation). The primary outcome measure for the trial was change in glycated haemoglobin (HbA1c) levels at 6 months and 12 months (see Box 1).

Design

The DESMOND Foundation study included a qualitative component, involving semi-structured interviews with people from the intervention group after attending DESMOND Foundation education sessions. The broad aim of the qualitative work was to contribute to the programme's evaluation in terms of helping to understand and explore the ways in which the education offered had an impact on those who attended, including changes in knowledge, attitudes and reported behaviour.

Recruitment and data collection

The DESMOND Foundation study consent procedure included the option of also agreeing to be contacted about the qualitative interviews; 86% provided this additional consent. The qualitative research team telephoned a purposive sample of participants who had indicated a willingness to be interviewed, to discuss the interviews further and to arrange a convenient time if they were still willing to contribute. The aim of our sampling strategy was

to include a range of people, for example, in terms of site (Leicester and Birmingham), gender, ethnicity and duration of diagnosis. The length of time between attending DESMOND and being interviewed ranged from within 1-2 months for just over half of the sample to over 12 months for some of the later interviews (median 5 months).

A flexible topic guide for the interviews was developed, and reviewed and revised during data collection. Briefly, topics included: level and source of diabetes-related knowledge prior to attending DESMOND; recall and perceptions of content of sessions; perceptions of how knowledge and behaviour had changed since attending DESMOND; and perceptions about use and format of sessions. Revisions after reviewing the first few interviews included limiting the focus on 'living with diabetes' given the plethora of research in this area, and the desire to focus on DESMOND-specific perceptions and experiences. In the current paper we report mainly on data relating to the first three of these four topic areas. After the first four interviews, it was apparent that interviewees were struggling to remember details about the DESMOND sessions. We asked the DESMOND designer to create a set of illustrated prompt cards showing the different sections of the education programme (using the same design as DESMOND materials used in the sessions), for the interviewer to use, where required, to trigger memories and stimulate discussion.

Semi-structured interviews were conducted face-to-face (NP, SR) in English or Gujarati in interviewees' homes. We had anticipated also conducting interviews in Urdu and Punjabi, but there were no interviewees who required facilitation in these languages. Interviews were digitally audio-recorded and transcribed verbatim, with simultaneous translation into English by a professional translator where required. Interview transcripts were reviewed during the course of data collection in order to determine the point at which saturation had

been reached; after completing 19 interviews, it was considered that new themes had ceased to emerge and areas of interest had been adequately explored.

Analysis

Analysis involved all authors and was based on identifying and exploring key themes and sub-themes. Our methods were informed by the constant comparative approach [29] and were designed to ensure that findings were grounded in the data. [30] Preliminary analysis of a sample of interviews was used to devise a provisional coding frame, in which we focused on three emergent themes which were considered to be very relevant to our aims: recall of learning from DESMOND, knowledge and motivation based on good news and bad news; and reported behaviour change following the intervention. This coding frame was subsequently used for coding the full dataset (SV), with ongoing discussions and revisions where required. NVivo qualitative data-indexing software was used to facilitate coding. Charting (SV,MS,HE) based on framework methodology [31,32] was subsequently used to organise the coded data for detailed review, exploration and interpretation, including comparisons between findings for people from different groups, for example, interviewees from different ethnic backgrounds, different age groups, and varying duration of T2DM.

Findings

Nineteen adults with T2DM, participating in the DESMOND Foundation study took part in the qualitative interviews. Ten interviewees were male; seven were from a White European background and 12 from ethnic minority backgrounds (South Asian n=11, African-Caribbean n=1); ages ranged from 43 to 83 years (median 59) and time since diagnosis ranged from 18 months to 22 years (median 7). Approximately half the sample were from each site (Leicester n=10; Birmingham n=9) and two of the 19 interviews were conducted in a combination of English and Gujarati.

Comparisons between people in different categories relating to ethnic origin, age and gender did not reveal any clear differences, for example, while there was a tendency for women, White Europeans and the oldest people to demonstrate lower levels of recall, these were not consistent findings across the whole qualitative sample. Poor or very limited recall of the education programme (see below) was demonstrated by those of both genders, from all ethnic backgrounds and ages. Our findings are therefore presented in relation to the overall sample. For this reason, and to protect anonymity, quotations are simply labelled with the interviewee's ID number (1-19).

General recall of programme content

Consideration of the extent to which interviewees recalled what they had learnt from the DESMOND sessions was complicated by the fact that it sometimes appeared difficult for interviewees to distinguish between learning that they had gained from DESMOND and from other sources. Overall, however, considerable variation was observed in terms of recall, and was not consistently related to time since attending DESMOND. Although a small minority of interviewees demonstrated what could be described as good recollection, the remainder demonstrated more limited or, in a few cases, poor recall:

'I do have to stop and think sometimes ... of course, we've had Christmas since.' (Int. 2)

This was particularly common before being shown the visual prompts, for example:

'I remember doing the games. We did two but I can't remember what they were.'

(Int. 15 – before prompt)

In some instances, however, interviewees described poor recall, but in fact demonstrated that, at a deep level, some of the activities in the programme had made an impression and some learning points had been assimilated:

Int. 6: Yes, there was quite a lot of things about foods [...] I can't remember them now ... like the cakes and the chocolate and the cheese and the things that they put on the food chart which had more fat and things like that.

Interviewer: Yes, one was the calories game and the sugar game, if you remember (shows visual prompt illustrating activities)

Int. 6: This one, yes, the amount of sugar in some of the Asian foods, yes, and the mango juice and the orange juice usually have more sugar in them than people expect. And then there was the – all of these had 100 calories – and how much more vegetables you get compared to the cheese or a small spoonful of oil.

Knowledge of bad news

Overall, interviewees indicated that prior to attending DESMOND they had limited knowledge of bad news messages about having T2DM. Around half of the sample mentioned that they had had some awareness of potential complications and the progressive nature of the condition prior to DESMOND, but this was frequently restricted to knowledge that people with T2DM may in time need insulin. Notably, no-one indicated that

they had been given bad news information at the time of diagnosis (although this may have been affected by recall given the range in time since diagnosis). Indeed prior knowledge of complications and progression of the condition was described as coming from work roles, independent knowledge-seeking through written materials or the internet, or from observations of family members with the condition, for example:

'I worked in the chiropody department, so, you know ... you see the other end of it, what happens if you don't look after yourself.' (Int. 11)

'... I found a website [and] listened to some lectures on that website. That's helped me quite a lot, and then I bought a book as well on diabetes' (Int. 6)

'My missus's uncle's son, they're diabetic, the family, most of them, his leg was amputated ... In the end he passed away'. [Int. 5]

Interviewees frequently described how DESMOND had provided new bad news awareness or reinforced their previous limited awareness. This new knowledge was attributed either to the learning from the session content, or to observations arising from the group format of the sessions, for example:

'They told us if sugar level is high, that will affect our eyes, kidneys, etc. and that they get worse. That also affects our heart, all nerves in our legs and all over in our body'

(Int.12)

'Interviewer: .. was that something you were aware of, all the complications that might arise?

Int. 9: Yeah, because I do have high blood pressure, so I knew it before, [...] I know it but you don't take it into account. But when you go for the [DESMOND] training, you learn more, blood pressure is high in diabetes, if it's high it's not good, you can get a stroke or a heart attack.

'And you learn a lot from other people [DESMOND participants] as well, when you see each other. Some people have got a problem with their feet and all that, you don't realise that.' (Int. 5)

DESMOND education sessions aim to facilitate increased biomedical understanding of what has gone wrong in the body when someone has T2DM. Some interviewees specifically described finding this aspect helpful in providing an explanation for the bad news and improving their overall awareness of the serious and progressive nature of the condition:

'The DESMOND course, I feel they're putting to the diabetic people that one of your body parts is not working properly ... I was aware, but if you don't remind yourself, then it will be [forgotten] easily. But with that course, it [awareness] is updated now' (Int. 3)

'One [of the most useful parts of the programme] was how diabetes actually affects the body, when you know and explain that it is cell and like a lock that gets rusted and can't open' (Int. 10)

Knowledge of good news

Although levels of reported prior awareness varied, all of the interviewees indicated some knowledge of good news messages before attending DESMOND. This was mostly linked to

the potential to control one's T2DM through diet, but also to the benefits of physical activity and the role of medication. As with bad news awareness, this prior knowledge had sometimes been derived from observations of family members:

'My mum's got diabetes, my aunt also ... she [mother] took care of herself when it came to her food, what she ate and how she ate' (Int. 17)

Unlike bad news messages, however, the majority of interviewees reported having received good news information from healthcare providers, at the time of diagnosis.

'My doctor was nice, he explained everything ... He used to tell me if you were eating two chapattis, cut down to one, if you were having a portion of rice, cut down to half, don't have too many grapes..' (Int. 5)

'I was interviewed [when diagnosed] by dieticians, diabetic experts, at the surgery and so on, well advised on what to eat, what not to eat, etc., lifestyle, changing it.'

(Int. 8)

Interviewees frequently talked about DESMOND having reinforced or increased their prior awareness of good news, by adding to their knowledge or helping them to think about diet and physical activity in different ways, for example in terms of sugar content, portion size or different ways of being active.

'I wasn't [previously] conscious of these things [sugar content] in the food because I don't think about food as if it contains sugar and calories and things ... but now I am more conscious ... now the vision of those young ladies who were teaching us comes into my mind, and I must be careful.' (Int. 4)

'You just refresh your mind really ... something [new] was concerning, regarding to eat a banana and grapes ... this has to be the small amount'. (Int. 19)

'In terms of learning about that [physical activity] ... you didn't realise ...like cleaning cars or something like that or doing the lawn. You would have thought it was just a job, you're not going to get any exercise from it, but apparently you do and it does get your heart rate working a bit harder and faster.' (Int. 16)

As with bad news information, the learning about biomedical understanding facilitated during DESMOND appeared to have helped people assimilate the good news messages, for example, by helping them to understand ways in which lifestyle changes and medication can help with blood glucose control and thus help to delay or prevent complications:

'I didn't know what metformin does in your body and the way the lady explained it, that it's the key to the cells and how it helps and, provided that you eat the right food, it's going to help ... that made a big difference and it really helped.' (Int. 17)

'They explained how the actual glucose needs to go into the cells and the cells are locked ... that you need to exercise, ... take your medicine and also watch the diet you eat, and that's the things that they said help unlock those cells.' (Int. 6)

Influence of bad and good news on motivation to change behaviour

Overall, exploration of the data in terms of comparing the influence of bad news and good news learning suggested that this varied according to the individual. Overall, however, it was noted that bad news appeared to be an important motivator. Interviewees who indicated that DESMOND had reinforced or added to their prior awareness of the bad news about

T2DM mostly described making changes to their lifestyle such as increasing physical activity or improving medication adherence.

Int. 12: Now I keep more control and do more exercise. [...]

Interviewer: What was the main reason compelled you to make changes in your life?

Int. 12: Complications arising from diabetes

'... so before [attending DESMOND], I knew it [about complications], but I didn't take it into account, but now I have to make sure I have my medicines on time'. (Int. 9)

Good news messages learnt through DESMOND about the benefits of modifying diet, increasing physical activity and taking medication as prescribed also appeared to have worked, as intended, by providing participants with the information they needed to make lifestyle changes.

'I used to love a digestive, a chocolate digestive biscuit, yeah. They said, "don't stop it, but instead of having two or three a day have two or three a week" ... I only have perhaps one or at the most two and then nothing for days after that ... so little things like that change you'. (Int. 8)

In some cases, interviewees also described benefits that they had experienced as a result of these changes.

'it [lifestyle] has changed a lot and the changes have brought my sugar levels down and I feel a lot better in myself and I've lost weight as well..' (Int. 16)

'I used to get up say five or six times in the night ... so now I mean, because of er changes in my food habits, sometimes I'll only go twice a night'. (Int. 13)

It was also apparent that for, some interviewees, the impetus to make changes was provided through a combination of positive and negative messages, confirming the benefits of providing both good and bad news. The interviewee cited above, for example, added that:

'It was just everything coming together; do you know what I mean? You understand then erm what it [diabetes] is, why it is, and what you can do to help you along' (Int. 13)

Individuals who did not report behavioural changes

Five interviewees did not specifically describe making any changes to their behaviour as a result of attending DESMOND, but this did not appear to be obviously linked to levels of recall, which ranged from poor to quite good in this group. The accounts of three of these people indicated that they had assimilated both good and bad news information from attending DESMOND. Some people in this category suggested that they had not felt the need to alter their behaviour after attending the education because they felt that they had already made relevant changes. One interviewee described how she had already been highly motivated by concern for her children:

'if I look after myself, then at least I'm there to look after my children until they're old enough to look after themselves'. (Int. 18)

Although they did not describe changes in behaviour as a result of attending DESMOND, those in this group all suggested that they had gained something from the education.

'I think I'm more better equipped now than I was ... now at least I know how my diabetes works, what happens in my body, whereas previously, my knowledge was not there' (Int. 10)

'I thought well, I've been doing that all these years, it's not done me any harm up to now, but I've got to watch it now ... I know if I'm doing wrong now' (Int. 15)

'I'd say it was more validated to what I what I was doing and it's made me even more aware and made me think positive that what I am doing, I'm on the right tracks' (Int. 18)

'I knew what it [diabetes] was all about in the first place, but it was a good day out and I enjoyed it really, you meet other people'. [Int. 1]

In spite of demonstrating some added bad news and also good news knowledge about T2DM, one interviewee openly acknowledged that she lacked motivation to make changes:

Interviewer: Okay, so since being on DESMOND, what kind of differences has it made to the management of your diabetes, if at all, if any?

Int. 14: Erm, not a lot, really, I know what I've got to do, I just can't motivate myself to do it at the moment

This interviewee spoke about barriers, for example, relating to the winter weather conditions limiting activity and a strong liking for chocolate affecting dietary modification.

She nevertheless indicated that the education had helped to provide awareness that might

act as a trigger for behaviour change in the future, for example, in relation to increased physical activity:

'I don't like this time of year anyway, so it's hard to motivate myself, but it is in the back of my mind that I do need to do something, so it's there but not there at the moment'. (Int. 14)

Thus, it appeared that, overall, the combination of negative and positive messages worked well in terms of stimulating people to make changes, with the bad news serving as a motivator – by highlighting the dangers – and the good news providing the solution – by equipping people with ways of averting or delaying the dangers. Even for those who failed to describe any immediate impact, there appeared to be some benefit in terms of heightened overall awareness, increased confidence, reassurance that the changes previously made were appropriate, or psychological benefit linked to meeting and interacting with other people with T2DM.

Discussion

Summary of main findings

Although recall of the DESMOND Foundation education sessions was often limited in our interviewees, they had all assimilated some learning and gained in some way from attending. A notable observation was that no-one reported that they recalled receiving any bad news messages about their condition from healthcare providers at the time of diagnosis, whilst most remembered being provided with good news information about potentially beneficial lifestyle changes, particularly relating to diet. In contrast, the DESMOND bad news messages about the progressive nature of T2DM and potential complications appeared to have been important motivators for behaviour change. Overall, the combination of bad and good news messages, incorporated into the DESMOND education programme appeared to have worked well in terms of providing motivation through negative messages and selfempowerment through enhanced self-management skills. Furthermore, for some people, biomedical learning about T2DM appeared to be pivotal for rationalising the good and bad news messages. Our findings suggest that the way in which these messages were balanced within the programme was effective in terms of a beneficial influence on overall illness perceptions. In our sample, we identified no clear differences in recall or learning between people in different categories relating to ethnic origin age or gender.

Given that the good and bad news message is a key principle in the DESMOND curriculum, it is perhaps unsurprising that interviewees' accounts show evidence of this learning, and that consequently this emerged as a key theme in our analysis. Notably, assimilation of these motivational messages was evident despite generally limited levels of recall about session content.

Fit with previous literature

By focusing on a particular educational approach within the DESMOND Foundation programme through interviewees' accounts, our study expands our knowledge of people's experiences of, and engagement with diabetes self-management education. Previous studies have identified the recommended categories of knowledge to be covered in such education as a baseline for participants to make and maintain lifestyle change [21] and the level of responsibility and involvement that should be fostered in participants [21,22]. Furthermore, in terms of the nature of such education, while there has been mixed reception of the group-based format, [20] a qualitative synthesis identified that support and information that is tailored and on-going nurtures effective self-management [22]. Our findings add to these observations by demonstrating how a particular educational approach – balancing bad and good news messages - can be incorporated into such programmes to help trigger behaviour change.

The complexity of giving people the 'right' amount of information about the risks and consequences of T2DM - to both encourage self-management and control psychological impact is not new [26] While bad news messages are essential to convey this knowledge, the sense of failure or self-blame from giving *only bad* news messages works against confident and flexible self-management. [21,28] Good news messages are required to foster an individual's ownership of the management of the condition, encourage further learning, and enhance self-confidence and quality of life. [22] Biomedical understanding of the underlying metabolic mechanisms leading to complications and of how lifestyle change can slow or change this, may also be insufficient on its own, but incorporated into a programme with combined bad and good news messages, it appears to serve to help rationalise this combination.

Strengths and limitations

In addition to contributing to the literature, our study was conducted in an ethnically diverse setting and we were able to include interviews with people who had attended education sessions specifically tailored to meet the needs of people from South Asian backgrounds.

The latter are an important target group for T2DM self-management education on account of increased prevalence of the condition [13,14] and poorer outcomes [33]. Our sample size of 19 interviews may be regarded as relatively limited, but recruitment was based on a purposive sampling strategy and the point at which interviewing was discontinued was based on our view that we had achieved adequate saturation in terms of emerging ideas and exploration of issues relevant to the focus of our research.

It is acknowledged that there may be some response bias in our sample, in relation to levels of self-management motivation, since we recruited from a pool of people who had made the decision to attend education sessions and agreed to participate in the interview study. This potential limitation is, however, unlikely to have had an important impact on the validity of our findings, which focus on understanding the ways in which the education worked for those who did attend.

We acknowledge that time may have played a part in interviewee's recall in different ways. First, the time between attending DESMOND and being interviewed (over 12 months for some) may have impacted on differing levels of recall of session content; although limited and poor recall was evident even in those interviewed within one month. Furthermore, DESMOND learning aims to have a lasting effect, given the long term nature of T2DM, so it was useful to interview people at varying time points. Second, the time since diagnosis (up to 22 years) may explain poor recall of bad news messages at diagnosis, but interviewees did recall good news messages from diagnosis, indicating that these were more prominent.

Implications

Our study participants attended DESMOND sessions designed for people with T2DM who had failed to receive timely information and support when newly diagnosed, either because this type of structured education was unavailable at that time, was not offered to them or because they chose not to attend. Our findings have, however, emphasised the importance of providing people with negative (bad news) as well as positive (good news) messages soon after diagnosis. Receiving a new diagnosis of T2DM is likely to be a worrying time for patients and there is also good evidence for a link between T2DM and depression. [34,35] It is thus understandable that health care providers may be reluctant to induce or heighten anxiety in newly diagnosed patients by alerting them to potential serious complications and the progressive nature of the condition, including the likelihood of needing insulin in the future. There is, therefore, a good argument for timely referral of newly diagnosed patients to structured education delivered by trained educators skilled in combining positive and negative messages. This may need to involve provision of on-going education, given our finding of fading recall; indeed an ongoing version of DESMOND is being evaluated. [36] Our study also highlighted the benefits of a sound theoretical basis to underpin the design of structured education. These implications are applicable beyond the management of T2DM, in the wider field of self-management education for people with chronic conditions.

Conclusions

Quantitative results from the main DESMOND Foundation trial, when available (see Box 1), will confirm whether or not the types of changes described by interviewees in our qualitative study had led to any improvements in health outcomes. Findings from this interview study have, however, highlighted ways in which the intervention appeared to have provided benefits to those who attended. More generally, our study has provided insights

into the way in which self-management education for people with chronic conditions may or may not work.

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Conflict of Interest Statement

The Authors declare that they have no conflicts of interest.

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Box 1. Context and setting - The DESMOND Foundation study

Trial registration number: ISRCTN25675619

<u>Study design</u>: Multi-centre cluster randomised controlled trial with randomisation at practice level. A qualitative sub-study was included in the overall design.

<u>Setting:</u> Participants were recruited to the trial through general practices (primary care centres) in two areas of the UK. Both areas have ethnically diverse populations including high numbers of people of South Asian origin: Leicester (South Asian residents mainly Gujarati speakers with origins in India) and Birmingham (South Asian residents mainly Punjabi / Urdu speakers with origins in Pakistan).

<u>Intervention</u>: Participants in the intervention group were invited to attend DESMOND Foundation structured group education. The format is group-based, typically involving 4-8 participants (who are welcome to bring a relative/friend), and delivered by trained educators. It is based on non-didactic delivery; the educators facilitate the sessions according to a set structure, with the aim that participants generate their own learning from the exercises and from each other.

Further information about the DESMOND Foundation programme is available on the DESMOND website: http://www.desmond-project.org.uk

Intervention delivery in the trial:

Three formats were offered:

- 1. standard delivery in English (6-hour programme: delivered as one session of 6 hours or two 3-hour sessions)
- 2. delivery in English with modified resources (food models) for South Asians (6-hour programme as above)
- 3. delivery in English with South Asian language interpretation and South Asian resources (12 hour programme: four 3-hour sessions).

Participants from control practices were contacted at the end of the 12-month study and offered a place on a DESMOND Foundation course

Eligibility: People with a diagnosis of type 2 diabetes (≥12 months) who had not previously attended diabetes group education. In diagnostic terms: a participant's glycated haemoglobin (HbA1c) reading needed to be between 7.0% (53 mmol/mol) and 11.0% (97 mmol/mol) inclusive, either at the baseline session or within 3 months prior to the date of the baseline session. For full eligibility criteria see:

http://www.controlled-trials.com/ISRCTN25675619

<u>Aims and quantitative outcome measures</u>: The overall aim of the trial was to evaluate the effectiveness of the education offered; the main quantitative outcome measures were based on changes in biomedical and psychosocial indicators relevant to type 2 diabetes.

<u>Sample:</u> 403 participants consented and were eligible to take part in the trial. 203 participants were randomised to the intervention arm, 135 of whom (67%) attended the DESMOND Foundation education.

Box 2: How DESMOND aims to provide motivation and self-management skills to encourage behaviour change, by providing bad news and good news.

The DESMOND programme is based on several underlying principles and theories [18-20]. The principle of focus in the current paper is the motivational tool of combining bad new with good news. In practice it aims to convey a bad news message - that poorly managed Type 2 diabetes will lead to potential threats to health and wellbeing - accompanied by a good news message – that by making certain lifestyle behaviour changes, these potential threats can be minimised, delayed or avoided. The aim of this approach is to help power the individual to self-manage their diabetes.

DESMOND Foundation Educator Manual and Curriculum

The manual provides information about the underpinning principle of bad and good news:

"...health care professionals are responsible for:

- Ensuring individuals with diabetes and their carers are provided with honest, up-to-date, evidence-based information regarding the causes, effects and options for the management of Type 2 diabetes.
- Ensuring people living with Type 2 diabetes are aware of their specific, ongoing health risks for developing complications..."

(DESMOND philosophy section)

Within the curriculum, educators are specifically provided with guidance about how to convey the bad news and good news message to participants:

"...although the session will contain some bad news, people will have the opportunity to gain knowledge and skills in how to prevent problems with their diabetes."

(Session content outline - Introduction and housekeeping)

"The messages today will contain some bad news. The good news is that the NHS recommends you come to sessions like DESMOND because the evidence tells us that complications are not inevitable and things can be done now to delay and prevent the worst of them. Most recent research has shown that controlling your diabetes earlier has benefits in the longer term ..."

(Example script - Introduction and housekeeping)

DESMOND Foundation Programme Content

While the DESMOND programme as a whole aims to present a combination bad news and good news messages, these messages are particularly prominent in the content of certain sessions: Bad news messages:

- The Professional Story 1: Type 2 Diabetes and Glucose (includes biomedical learning)
- The Professional Story 2: Risk Factors and complications (includes biomedical learning)

Good news messages:

- Monitoring: How Can Your Do it?
- Taking Control 1: Food choices: Glycaemia and Insulin Resistance
- Physical Activity
- Taking Control 2: Food choices: Focus on Fats and Cardiovascular Disease
- Self Management Plan

Further information is available from the DESMOND website: http://www.desmond-project.org.uk/