

Barriers to structured diabetes education attendance: Opinions of people with diabetes

Muli Lawal, Anthony Woodman, Joelle Fanghanel

The NICE diabetes guidelines recommend structured education, with an annual update, for every person newly diagnosed with diabetes. It is undeniable that people will need to attend the education sessions in order to reap their benefits, but promoting attendance at diabetes education centres can sometimes be problematic. The aim of this study was to explore the barriers associated with non-attendance at diabetes education sessions in the UK. A qualitative approach was adopted using telephone interviews with 24 people with newly diagnosed type 2 diabetes who did not attend their appointments following referral from general practice. Thematic analysis was used to analyse the data. The identified barriers could be grouped into three categories: personal circumstances, individual perceptions and healthcare protocols. Whilst some of the barriers have simple solutions, it may be challenging to mitigate some others.

In spite of significant medical advancement in care, diabetes remains a growing global concern. The estimated global cost of diabetes in 2015 was US\$1.31 trillion (Bommer et al, 2017), and the American Diabetes Association (2013) states that the increase in the cost of treating type 2 diabetes could outgrow the national gross domestic product of some countries unless this is addressed. Similarly, the cost of prescribed antidiabetes drugs in the UK rose from £572.4 million to £983.7 million between 2006/07 and 2016/17 (NHS Digital, 2017). Apart from the organisational healthcare costs, diabetes is a lifelong condition that affects people from all socioeconomic backgrounds, and it has a significant impact on the physical, social, economic and psychological wellbeing of the affected people (Lawal, 2016; Public Health England, 2018).

Several studies have identified the benefits of diabetes education in promoting self-care abilities and reducing preventable complications. Diabetes education programmes improve individuals' knowledge of diabetes, reduce complications and

hospital admissions, and promote healthy lifestyles (Davies et al, 2008; Rygg et al, 2012). Therefore, a key global healthcare policy response has been to emphasise empowerment through education. Structured patient education forms part of the World Health Organization (2016), National Service Framework for Diabetes (Department of Health, 2001) and NICE (2017) recommendations for managing diabetes.

Although it is acknowledged that diabetes services in the UK and other parts of the world are improving, there is a need for further improvement, particularly in promoting structured patient education. The statistics show that people with diabetes often fail to attend the structured education sessions for a range of reasons (Schäfer et al, 2013; Winkley et al, 2015; Lawal, 2016). Two recent systematic reviews conducted on this phenomenon identified limited studies and established the need for further research on this topic (Lawal, 2014; Horigan et al, 2017). Therefore, the current study was conducted to contribute insights into

Citation: Lawal M, Woodman A, Fanghanel J (2018) Barriers to structured diabetes education attendance: Opinions of people with diabetes. *Journal of Diabetes Nursing* 22: JDN038

Article points

1. It is important not to assume that people with diabetes will engage with a beneficial healthcare intervention.
2. Barriers that may hinder the uptake of structured diabetes education include the complexity of individual circumstances and motivation.
3. Changing the way practitioners provide information, follow up with patients and support them could aid attendance.

Key words

- Barriers to therapy
- Concordance
- Structured diabetes education

Authors

Muli Lawal is Senior Lecturer; Anthony Woodman is Deputy Vice-Chancellor and Provost for Health; Joelle Fanghanel is Pro-Vice-Chancellor (Academic), all at University of West London

Page points

1. Twenty-four people with newly diagnosed type 2 diabetes who had not attended structured diabetes education after referral underwent semi-structured interviews via telephone.
2. Reasons for not attending can be grouped into three overarching themes: personal circumstances, individual perceptions and healthcare protocols.

barriers that may hinder the uptake of structured diabetes education.

Methods

Research design

In bridging the identified gap in research on this problem, this second-phase study was designed as a follow-up to explore the findings from a series of focus group interviews with healthcare professionals (Lawal et al, 2017). To address the research question, the authors used one-to-one telephone interviews with people with newly diagnosed diabetes who did not attend a diabetes education programme after referral.

Sample and setting

In accordance with the UK national diabetes management policy, all newly diagnosed people with diabetes are referred to attend diabetes education sessions. The participants were recruited through the hospital database of these newly diagnosed people. They were drawn from four diabetes education centres with different demographic characteristics and high attrition rates in south east England. The study employed a convenience sample of participants who were willing to volunteer information. In total, 102 people were approached to take part in the study but only 24 consented, for various reasons listed in *Box 1*. Each telephone number was called three to five times.

Data collection procedures

Semi-structured interviews were conducted by an experienced researcher with a written guide to facilitate discussion on the topic of barriers and enablers to attendance at diabetes structured education. The question guide was developed based on the literature review and data generated from phase 1 of the study (Lawal, 2014; Lawal et al, 2017). The investigator conducted the one-to-one interviews by telephone in an office within the hospital Trust, and each interview lasted between 5 and 10 minutes. The researcher used a conversational style and recorded answers to questions regarding participants' personal characteristics.

Ethical implications

The research followed the principles outlined in

Box 1. Reasons for not participating in the present study.

- No response
- Repeated voicemail answer
- Number not recognised
- Unavailable for telephone conversation but willing to receive a text message
- Presently sick in hospital
- On holiday
- Stated that they had attended education

the Declaration of Helsinki and was conducted according to the ethical codes guiding research in Great Britain. Ethics approval was granted by Berkshire Research Ethics Committee and permission was received from the Clinical Research Development Unit of Berkshire East Primary Care Trust. Similarly, each participant's consent was sought at the beginning of each telephone interview.

Data analysis

The researchers performed thematic analysis to identify barriers to attendance using an inductive approach to build a descriptive narrative of the phenomenon (Polit and Beck, 2012). Coded data were analysed to identify themes and subthemes to illustrate the issues affecting attendance.

Results

Twenty-four people contributed their views during a one-to-one telephone interview. All participants were 40 years of age and older, with a mean age of 52.9 years (range, 44–68 years), and included men and women. All participants were newly diagnosed with diabetes; the duration of diabetes was 1–2 years and the mean time since diagnosis was 1.2 years. There were slightly more male participants than female (13 male, 11 female). The study population comprised people from different ethnic backgrounds: 12 Caucasian (50%), eight Asian (33%) and four African/Caribbean (17%).

Quotes are provided as examples of each participant's responses. Based on thematic analysis, the main areas of findings are discussed under three broad themes, as shown in *Box 2*.

Theme 1: Personal circumstances

An individual is unique and our circumstances

Box 2. Themes identified from one-to-one interviews.**Theme 1: Personal circumstances**

- Illness
- Work commitments
- Childcare
- Weather conditions
- Away on holiday
- Forgetfulness

Theme 2: Individual perceptions

- Lack of interest
- Perceived nature of diabetes
- Perceived knowledge of diabetes and access to other sources of information

Theme 3: Healthcare protocols

- Referral system
- Communication barrier
- Mode of education delivery

differ at different times. In this study, participants divulged various personal difficulties and barriers to attendance, which will be discussed under the following subthemes.

Illness

Being ill during the allocated time was mentioned by the participants: *"I was very poorly and cannot attend"* (Interviewee 11); *"I was sick and couldn't come because I had bronchitis"* (Interviewee 19); and *"I am not well enough to attend the session"* (Interviewee 6).

Work commitments

Some of the interviewees attributed their reason for non-attendance to work-related problems: *"It was in the afternoon and I went to work and got caught in the traffic"* (Interviewee 5); and *"I was working on that day"* (Interviewee 4).

Childcare

Some participants cited childcare issues as the reason that prevented them from attending the session: *"Sometimes I have to attend to my grandchildren because my daughter is working"* (Interviewee 10).

Weather conditions

A few respondents stated that they could not attend

due to unforeseen circumstances, such as bad weather: *"You will find that day was a bad day and most people couldn't go out because it was snowing heavily"* (Interviewee 17).

Holiday

Some respondents were out of the country during the planned sessions; therefore, it was impossible to attend the sessions: *"Gone to Australia for 1 month"* (Interviewee 7).

Forgetfulness

Some participants identified forgetfulness as the reason for their non-attendance: *"Sorry, I forgot about it completely"* (Interviewee 16); *"I did not remember at all"* (Interviewee 22); and *"I messed up really because I've got problem at work then"* (Interviewee 14).

Theme 2: Individual perceptions**Lack of interest**

Absence of the desire to attend the education sessions for certain personal beliefs or behaviours was revealed by the data: *"I don't really want to come because I am fine"* (Interviewee 3); *"I am not interested"* (Interviewee 20). Some participants showed complete lack of interest in the session: *"No, I am quite happy even if I don't know everything. No thank you. It was unnecessary and I don't know why they are bothering me"* (Interviewee 13); and *"Nothing in particular"* (Interviewee 2).

Perceived nature of diabetes

Considering the time since diagnosis, some respondents did not attend because of their personal perception about the seriousness of diabetes: *"I am really pre-diabetic and I have taken some test and I am no longer pre-diabetic"* (Interviewee 24). In a similar way, some respondents did not attend because they had the opinion that they were all right: *"I am quite comfortable"* and *"My diabetes is well controlled"* (Interviewee 3); and *"I am doing everything right and my blood sugar level is okay"* (Interviewee 23).

Perceived level of knowledge and access to other sources of information

Some respondents demonstrated lack of interest by saying: *"Also, my son-in-law knows a lot about it because he is a health professional"* (Interviewee 15).



Read more online

Barriers to attendance at diabetes education centres: Perceptions of education providers

Part 1 of this study, in which the authors interview education providers about their perceived barriers to uptake of structured diabetes education.

Journal of Diabetes Nursing
21: 61–6

Available at:

<https://is.gd/lawal2017>

“These findings confirm the importance of considering these personal problems and demographic characteristics when providing necessary interventions.”

Another respondent stated that he could find out more information from other sources: *“I can find out more information on the internet”* (Interviewee 15).

Theme 3: Healthcare protocols

Some of the respondents identified certain administrative constraints that hindered their attendance, as follows.

Referral system

Some respondents stated that: *“I didn’t because I couldn’t find my way, eh, I mean I got lost because I trekked”* (Interviewee 1); and *“I was due to go to one earlier and I cancelled it and nobody contacted me”* (Interviewee 9). The interviewees shed more light on this issue by stating that the invitation was by telephone in some cases and adequate information to guide their attendance was not given: *“No, I didn’t have a letter to specify the place; it was a telephone message from a lady”* (Interviewee 1); *“I did not attend because I didn’t get a letter”* (Interviewee 2); and *“No, unfortunately, I didn’t get a letter”* (Interviewee 8).

Communication barriers

When asked whether they were willing to attend the session next time, most of the interviewees stated they were willing to attend based on the current information. This suggests that adequate information may aid attendance. Some of the illustrative quotes are thus: *“Yes, if I can get a letter, then I would attend”* (Interviewee 1); *“I have been expecting someone to call me to book me for another session but that has not happened”* (Interviewee 9); *“Please can you give me the appointment line”* (Interviewee 8); *“Yes, I would be happy to attend another session if I know about it”* (Interviewee 17); and *“Yes. If I am not working. That means if I can be given some dates in advance”* (Interviewee 18).

Mode of education delivery

Most participants had no issue with attending group, as opposed to one-to-one, education and this was verbalised thus: *“No, that would not be a problem”* (Interviewee 2); *“Yes, it is fine by me”* (Interviewee 4); *“No, I don’t have any problem with that”* (Interviewee 12) and *“It would be interesting to have people with the same problem sharing their experience”* (Interviewee 21). Two participants

expressed their flair for group education by saying: *“I was not aware before but that’s fine. Even if I am late, I would join – just be part of the group. You get to learn from other people as well and I have attended similar sessions in the past”* (Interviewee 5); and *“It will be good to hear information from other people to help each other”* (Interviewee 14). One participant stated that he would need to attend the session before offering an appropriate comment on this question: *“Ehm – I don’t really know because I have not been yet. So I need to attend to find out more”* (Interviewee 19).

Discussion

Compliance, adherence and concordance are popular terms in care management, and these concepts are applicable to health education. Concordance with self-care education is important in preventing complications and promoting health.

Participants in our study were aged 44–68 years, with a mean age of 53 years. Epidemiological evidence has shown that type 2 diabetes is common among this age group (Brashers et al, 2016). Our study showed that the attrition rate was influenced by various personal-life problems, ranging from work-related issues to childcare problems and ill health. Gucciardi (2012), Winkley et al (2015) and Lawal et al (2017) have all identified conflicting personal circumstances to be a barrier to attendance, and this is congruent with the findings of this study. These findings confirm the importance of considering these personal problems and demographic characteristics when providing necessary interventions.

Our findings revealed that some respondents did not attend because of their perception about the level of diabetes knowledge they possessed, or because they believed they could gain sufficient information by searching the internet or through family discussions. This result corroborates the findings of Winkley et al (2015), who found lack of perceived benefits of diabetes education to be a barrier to attendance. Diabetes has a genetic predisposition (Brashers et al, 2016), so individuals with diabetes are likely to have a relative with the condition. Additionally, the duration of diabetes could be a contributory factor due to lack of understanding about the progressive impact of beta-cell dysfunction (Brashers et al, 2016). Although informal education is increasingly becoming a key source

of health education, it has its flaws (Lawal, 2016). Consequently, it is important to reinforce the superiority of structured education and the short- and long-term complications of diabetes.

Our data suggested that some participants were not at all interested in structured education, while others claimed to have forgotten about it. It could be argued that the latter group used forgetfulness as an excuse to cover their lack of interest, but this forgetfulness could equally have been due to old age, the added stress of recognising the severity of the condition, or other personal or family issues in their life at that time (Lawal, 2016). It could also be due to stigma, as stigma and shame contribute to lack of uptake of diabetes education in some people (Winkley et al, 2015). Whilst it can be assumed that people need to rearrange their appointments if they cannot make them due to circumstances such as a bad weather or a holiday, an individual who is ashamed is unlikely to make such effort.

Interestingly, this study showed that the group nature of structured education was not a barrier to attendance for people with diabetes. This is in contrast with the perceptions of structured education providers, who believed that group education could be off-putting for some (Lawal et al, 2017). Some studies have compared the benefits of individual versus group diabetes education, with conflicting results (Gucciardi et al, 2007; Duke et al, 2009); however, NICE (2017) recommends that individual preferences for either group or individual education should be considered.

This research showed that a poor appointment system with ineffective practitioner–patient communication has a role to play in non-attendance. The impact of poor communication on healthcare practice is well documented in the literature and this finding is consistent with other studies (Gucciardi et al, 2012; Winkley et al, 2015; Lawal et al, 2017). These results suggest the need to improve appointment and referral systems. In relation to communication with people with diabetes, NHS England (2018) has recently set out principles of good practice, which emphasise a collaborative and engaging communication style.

Other authors have identified several measures that can improve attendance rates. These include improving referral and appointment systems, offering flexible options for time and location,

and reducing waiting times between referral and attendance (Winkley et al, 2015; Lawal et al, 2017). Pender (2016) states that offering a taster session, informing employers about the impact of diabetes, raising awareness and providing a straightforward invitation can help to improve attendance. In addition, it is important for practitioners to be aware that diabetes-related stigma exists among some individuals (Winkley et al, 2015).

Study strengths and limitations

Strategies were employed to enhance rigour and to minimise researcher bias through verbatim representation of views. Saturation was achieved at a point that no new barriers were forthcoming (Polit and Beck, 2012). In conducting research of this nature, access to participants can pose serious difficulties; therefore, a key limitation of the study was the use of the convenience sampling technique. To mitigate this, the study's population was drawn from four diverse geographical areas with different demographic characteristics.

Conclusion

The national and international response to diabetes prevention includes empowerment, and structured patient education has a proven part in this. Nevertheless, it is important not to assume that people will automatically attend a referral from a medical professional just because it is beneficial for them. Instead, healthcare providers and educators need to identify additional support that people with diabetes may need to ensure attendance after invitation.

The findings of this study elucidate the barriers to successful education for people with diabetes, which include the individual's circumstances, motivation, perceptions and beliefs, as well as the method of invitation and referral. The findings also suggest that the way practitioners provide information, follow up with patients and support them could aid attendance.

A better understanding of the barriers could facilitate the design of appropriate interventions to mitigate them. Therefore, we recommend further study to investigate the motivating factors of people who have attended structured education, because data triangulation may contribute to better understanding of this phenomenon. ■

Measures to improve attendance at structured education

1. Improve referral and appointment systems.
2. Allow flexible options for time and location.
3. Reduce waiting times between referral and attendance.
4. Offer taster sessions.
5. Inform employers and raise awareness about the impact of diabetes.
6. Provide a straightforward invitation.
7. Consider the impact that shame and stigma may have on attendance.

“Healthcare providers and educators need to identify additional support that people with diabetes may need to ensure attendance after invitation.”

- American Diabetes Association (2013) Standards of medical care in diabetes – 2013. *Diabetes Care* **36**(Suppl 1): S11–66
- Bommer C, Heeseemann E, Sagalova V et al (2017) The global economic burden of diabetes in adults aged 20–79 years: a cost-of-illness study. *Lancet Diabetes Endocrinol* **5**: 423–30
- Brashers VL, Jones RE, Huether SE (2016) Alterations of hormonal regulations. In: Huether SE, McCance KL (editors). *Understanding Pathophysiology* (6th edition). CV Mosby, Maryland Heights, MO, USA: 460–89
- Davies MJ, Heller S, Skinner TC et al (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* **336**: 491–5
- Department of Health (2001) *National Service Framework for Diabetes: Standards*. DH, London. Available at: <https://bit.ly/2AXENme> (accessed 09.08.18)
- Duke SA, Colagiuri S, Colagiuri R (2009) Individual patient education for people with type 2 diabetes mellitus. *Cochrane Database Syst Rev* (1): CD005268
- Gucciardi E, Chan VW, Lo BKC et al (2012) Patients’ perspectives on their use of diabetes education centres in Peel–Halton region in southern Ontario. *Can J Diabetes* **36**: 214–17
- Horigan G, Davies M, Findlay-White F et al (2017) Reasons why patients referred to diabetes education programmes choose not to attend: a systematic review. *Diabet Med* **34**: 14–26
- Lawal M (2014) Barriers to attendance in diabetes education centres: a systematic review. *Diabetes & Primary Care* **16**: 299–306
- Lawal M (2016) *Implementation of Diabetes Education Policy: Prospects and Barriers*. Lambert Academic Publishing, Düsseldorf, Germany
- Lawal M, Woodman A, Fanghanel J, Ohl M (2017) Barriers to attendance at diabetes education centres: perceptions of education providers. *Journal of Diabetes Nursing* **21**: 61–6
- NHS Digital (2017) *Prescribing for Diabetes, England – 2006/07 to 2016/17*. NHS Digital, Leeds. Available at: <https://bit.ly/2AWrYbT> (accessed 09.08.18)
- NHS England (2018) *Language Matters: Language and diabetes*. NHSE, London. Available at: <https://bit.ly/2tpAmt9> (accessed 13.08.18)
- NICE (2017) *Type 2 diabetes in adults: management* [NG28]. NICE, London. Available at: www.nice.org.uk/guidance/ng28 (accessed 09.08.18)
- Pender S (2016) What nurses can do to improve attendance at structured education programmes. *Journal of Diabetes Nursing* **20**: 160–2
- Polit DF, Beck CT (2012) *Nursing Research: Generating and Assessing Evidence for Nursing Practice* (9th edition). Lippincott Williams and Wilkins, Philadelphia, PA, USA
- Public Health England (2018) *Health matters: preventing type 2 diabetes*. PHE, London. Available at: <https://bit.ly/2kjYDgc> (accessed 09.08.18)
- Rygg LØ, Rise MB, Grønning K, Steinsbekk A (2012) Efficacy of ongoing group based diabetes self-management education for patients with type 2 diabetes mellitus. A randomised controlled trial. *Patient Educ Couns* **86**: 98–105
- Schäfer I, Küver C, Wiese B et al (2013) Identifying groups of nonparticipants in type 2 diabetes mellitus education. *Am J Manag Care* **19**: 499–506
- Winkley K, Ewvriehoma C, Amiel SA et al (2015) Patient explanations for non-attendance at structured diabetes education sessions for newly diagnosed type 2 diabetes: a qualitative study. *Diabet Med* **32**: 120–8
- World Health Organization (2016) *World Health Day 2016: Beat diabetes*. WHO, Geneva, Switzerland. Available at: <https://bit.ly/1N736rZ> (accessed 09.08.18)