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

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## NON-ATTENDANCE IN DIABETES EDUCATION SESSIONS IN THE UK: OPINION OF PATIENTS

The UK's National Institute for Health and Care Excellence (NICE) diabetes guidelines recommend structured patient education with an annual update for every newly diagnosed patient. It is undeniable that patients 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 (n=24) of newly diagnosed patients with type 2 diabetes who failed to attend their appointments following referral from their general practice surgeries. Thematic analysis was used to analyse the data. Researchers found that various personal reasons such as work, childcare problems, bad weather, holidays and ill-health were responsible for non-attendance. The study identified barriers relating to perceived seriousness of the medical condition and potential benefits of attending diabetes education sessions. Additionally, the process of inviting patients had an influence on attendance. Whilst some of the reasons require a simple solution, it may be challenging to mitigate some others.

### **Introduction**

In spite of the significant medical advancement in diabetes care, diabetes remains a growing global concern (Lawal 2016, WHO 2016, Public Health England 2018). 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 (GDP) of some countries unless this is addressed. Similarly, the cost of prescribed anti-diabetes drugs rose from £572.4 million to £983.7 million in the United Kingdom 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 socio-economic backgrounds and it has a significant impact on physical, social, economic and psychological wellbeing of the affected person (Lawal 2016, Public Health England 2018).

Several research studies have identified the benefits of diabetes education in promoting self-care abilities and reducing preventable complications. Diabetes education programmes improve patients' 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 (NSF) for diabetes (Department of Health 2001), and NICE (2017) recommendations for managing diabetes in the United Kingdom.

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 patients often fail to attend the structured patient education sessions for a range of reasons (Lawal 2016;

Winkley et al 2014; Schafer et al 2013). Two recent systematic reviews conducted on this phenomenon established limited studies and the need for further studies on this topic (Lawal 2014, Horigan et al 2017). This is therefore an under-researched area, particularly in the UK; hence, this study will contribute insights to barriers that may hinder the uptake of diabetes education.

### **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 the focus group interviews with practitioners (Lawal 2017). To address the research question, this study used a one-to-one telephone interview with patients who failed to honour an invitation to attend a diabetes education programme.

### **Sample and setting**

In accordance with the UK national diabetes management policy, all newly diagnosed patients with diabetes are referred to attend diabetes education sessions. Participants were recruited through the hospital database of these newly diagnosed patients with diabetes. The study participants 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 that were willing to volunteer information. 102 participants were approached to take part in the study but only 24 consented due to various reasons itemized in table 1. Each telephone number was called three to five times.

Table 1 – Barriers to telephone access

- |                                                                                                                                                    |
|----------------------------------------------------------------------------------------------------------------------------------------------------|
| <ul style="list-style-type: none"><li>- Repeated voice mail answer</li><li>- Presently sick in the hospital</li><li>- No response at all</li></ul> |
|----------------------------------------------------------------------------------------------------------------------------------------------------|

- |                                                                                                                                                                                                                                                 |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <ul style="list-style-type: none"><li>- On holiday</li><li>- Patients stated that they have attended</li><li>- Number not recognised</li><li>- Unavailable but you can send a text</li><li>- Telephone kept ringing without an answer</li></ul> |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

### **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 in diabetes education centres. The question guide was developed based on the literature review and data generated from phase 1 of the study. The investigator conducted the one-to-one interviews by telephone in an office within the hospital trust and each interview lasted between five and ten minutes. The researcher used a conversational style and recorded answers to questions regarding their personal characteristics.

### **Ethical implications**

The research followed the principles outlined in 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 patient'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 sub-themes and themes to illustrate the issues affecting attendance.

## **Results**

Twenty-four non-attenders contributed their views during a one-to-one telephone interview and the 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 table 2 below:

**Table 2. Summary of findings**

<p><b>Theme 1 – Personal circumstances</b></p> <ul style="list-style-type: none"><li>- Illness</li><li>- Work commitments</li><li>- Child care</li><li>- Weather conditions</li><li>- Away on holiday</li><li>- Forgetfulness</li></ul>
<p><b>Theme 2 – Individual perception</b></p> <ul style="list-style-type: none"><li>- Lack of interest</li><li>- Perceived nature of diabetes</li><li>- Perceived knowledge of diabetes and access to other sources of information</li></ul>
<p><b>Theme 3 – Official protocol</b></p> <ul style="list-style-type: none"><li>- Referral system</li><li>- Communication barrier</li></ul>

- Mode of education delivery

### Characteristics of the participants

All participants were 40 years of age and older with mean age of 52.9 years (age range 44–68 years) and included men and women (table 3). All participants were newly diagnosed patients with diabetes and the duration of living with diabetes was 1–2 years and the mean year of diagnosis is 1.2 years. There is a slight difference in gender with few more male participants than female (13 male, 11 female). The study population is comprised of participants from different ethnic backgrounds: 12 Caucasian (50%), 8 Asian (33%) and 4 African/Caribbean (17%).

Table 3 - Characteristics of participants (n=24)

Age in years	52.9 years (44-68)
Years with diabetes	1.2 (1-2 years)
Sex	13 male, 11 female
Ethnicity	Caucasian (12), Asian (8), Black African/Caribbean (4)

### Theme 1 –Personal circumstances

An individual is unique and our circumstances are also different from time to time. For this study, patients divulged various personal difficulties and these barriers will be discussed under the following sub-themes:

#### Illness

Been ill during the allocated time was mentioned by the participants: *“I was very poorly and cannot attend”* (Interviewee T11), *“I was sick and couldn’t come because*

*I had bronchitis*" (Interviewee T19) and *"I am not well enough to attend the session"* (Interviewee T6).

### **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 T5) and *"I was working on that day"* (Interviewee T4).

### **Child care**

Some patients cited child care issue as the reason that prevented them from attending the session: *"Sometimes I have to attend to my grandchildren because my daughter is working"* (Interviewee T10).

### **Weather condition**

A few respondents stated that they could not attend due to some 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 T17).

### **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 T7).

## **Forgetfulness**

Participants identified forgetfulness as the reason for their non-attendance: “*Sorry, I forgot about it completely* (Interviewee T16), “*I did not remember at all*” (Interviewee T22) and “*I messed up really because I’ve got problem at work then*” (Interviewee T14).

## **Theme 2 – Individual perception**

### **Lack of interest**

Absence of the desire to attend the education sessions for certain personal thought or behaviour was revealed by the data: “*I don’t really want to come because I am fine*” (Interviewee T3), “*I am not interested*” (Interviewee T20). Some patients’ showed complete lack of interest in the session by saying: “*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 T13) and “*Nothing in particular*” (Interviewee T2).

### **Perceived nature of diabetes**

Considering the duration of 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 T24). In a similar way, some respondents did not attend because they have the opinion that they are alright: “*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 T23).

### **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 T15). Another respondent stated that he can find out more information from other sources such as the internet: *"I can find out more information on the internet"* (Interviewee T15).

### **Theme 3 – Official protocol**

Some of the respondents identified certain administrative constraints that hindered their attendance:

#### **Referral system**

Some respondents verbalized that: *"I didn't because I couldn't find my way, ehm, I mean I got lost because I trekked"* (Interviewee T1) and *"I was due to go to one earlier and I cancelled it and nobody contacted me"* (Interviewee T9). The interviewees shed more light on this issue by stating that the invitation was by telephone conversation 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 T1), *"I did not attend because I didn't get a letter"* (Interviewee T2) and *"No, unfortunately, I didn't get a letter"* (Interviewee T8).

#### **Communication barrier**

When asked whether they are willing to attend the session next time, most of the interviewees stated they are willing to attend based on the current information. This may further suggest that adequate information may aid attendance. Some of the illustrative data are thus: *"Yes, if I can get a letter, then I would attend"* (Interviewee

T1), *“I have been expecting someone to call me to book me for another session but that has not happened”* (Interviewee T9), *“Please can you give me the appointment line”* (Interviewee T8), *“Yes, I would be happy to attend another session if I know about it”* (Interviewee T17) 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 have no issue with attending group education and this was verbalised thus: *“No, that would not be a problem”* (Interviewee T2), *“Yes, it is fine by me”* (Interviewee T4), *“No, I don’t have any problem with that”* (Interviewee T12) and *“It would be interesting to have people with the same problem sharing their experience”* (Interviewee T21). 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 session in the past”* (Interviewee 5) and *“It will be good to hear information from other people to help each other”* (Interviewee 14). A participant stated that he will 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. Thus, concordance with self-care education is important in preventing complications and promoting health. Patients 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, Jones and Huether 2017). The findings in 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. In a similar fashion, Gucciardi (2012), Winkley et al (2014), Lawal (2017) and Coates et al (2018) have all identified conflicting personal circumstances to be a barrier to attendance and this is congruent with the findings of this study. Therefore, our findings confirm the importance of considering these personal problems and demographic characteristics when providing necessary interventions.

The findings of this study revealed that some respondents did not attend because of their personal perception about the level of diabetes knowledge they possessed, or they believed they could gain sufficient information by searching the web or through family discussions. This result corroborates the findings of Winkley et al (2014) which found perceived benefits of diabetes education as a barrier to attendance. Incidentally, diabetes has a genetic predisposition (Brashers, Jones and Huether 2017), so individual patients' are likely to have a relative with diabetes. Additionally, the duration of diagnosis could be a contributory factor due to lack of understanding about the progressive impact of beta cell dysfunction (Brashers, Jones and Huether 2017). 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 a structured education and the short and long term complications of diabetes.

The data suggested that some patients were not at all interested in the teaching sessions. It could be argued that they are using forgetfulness as an excuse to cover their lack of interest, but this may equally be due to old age, added stress of recognising the severity of the disease, or due to other personal or family issues in their life at that time (Lawal 2016). It could also be due to stigma because Winkley et al (2014) found that stigma and shame contributes to lack of uptake of diabetes education in some patients. Whilst, it can be assumed that the patients need to re-arrange their appointments if they cannot make it due to circumstances such as a bad weather conditions or a holiday, a patient that is ashamed is unlikely to make such effort. Nevertheless, the finding of wrong telephone number on the record (table 1) may require the co-operation of the patient to update their record.

Interestingly, the findings showed that group education was not a barrier to attendance. This is in contrast with the findings of Lawal et al (2017) which indicated that group education could constitute a barrier. 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) indicated 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 literature and this finding is consistent with other studies (Gucciardi et al 2012, Winkley et al 2014, Lawal 2017), and therefore suggest the need to improve the appointment system. In relation to diabetes care, NHS England (2018) sets out principle of good practice which emphasise collaborative and engaging communication style.

The National Health Service in England is a publicly funded organisation providing free quality service for citizen, however it is now confronted with immense financial pressure(Baggott 2010) due to an ageing population, growth in population generally, technological advancements and high costs of new drugs and interventions. Therefore, there is a need to promote ways to improve attendance in order to prevent unnecessary wastage regardless of the cost of service. Other authors have identified several measures such as improved referral and appointment systems, offering flexible option of time and location, reduced waiting time between referral and attendance (Winkley 2015, Lawal 2017) in improving the attendance rate. Pender (2016) states that offering a taster session, informing employers about the impact of diabetes, raising awareness and providing a straight forward invitation are tips to improve attendance. In addition, it is important for the practitioners to be aware that diabetes related stigma exist among some patients (Winkley et al 2014).

### **Strengths and limitations of the study**

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 because structured patient education has proven to be useful in diabetes management. Nevertheless, it is important not to assume that patients will automatically honour an invitation from a medical professional just because it is beneficial for them. Instead, healthcare providers and educators need to identify additional support patients may need to ensure attendance after invitation. The findings of this study elucidate the barriers to successful education for patients with diabetes and this includes the complexity of individual circumstances, individual motivation, perceptions, beliefs and the method of invitation. The findings from this study suggest that how practitioners provide information, follow-up with patients and support them could aid attendance. Our study suggests that a better understanding of the barriers could facilitate the design of appropriate interventions to mitigate the barriers. Therefore, we recommend further study to investigate the motivating factors of those that have attended, because data triangulation may contribute to the understanding of the phenomenon.

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### Article points

- Despite the significant medical advancement in diabetes care, diabetes remains a global public health problem.
- A key international healthcare policy for diabetes is empowerment through education.
- It is important not to assume that patients will engage with a beneficial healthcare intervention.

- Barriers that may hinder the uptake of diabetes education include complexity of individual circumstances and motivation.
- Practitioners-patient relationship, support and follow-up may aid attendance.

**Key words**

- Health education
- Empowerment
- Diabetes care
- Adherence
- Concordance