

Exploring diabetes non-attendance: An Inner London perspective

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Missed diabetes appointments are a substantial cost to the NHS and put the individual at risk of worse health outcomes due to inadequate self-management and the development of avoidable complications. Recent research demonstrated that the diabetes service in the London Borough of Newham had a yearly non-attendance rate of around 25%. Therefore, a qualitative study was conducted to determine the reasons why frequent non-attenders were unable or unwilling to attend their appointments. The emergent themes reveal a number of factors that can be addressed to improve attendance, particularly in areas of high deprivation and cultural diversity, such as Inner London.

During 1996 and 1997, 6 million healthcare appointments were missed, at an estimated cost to the NHS of £300 million (Department of Health [DH], 1997). In 2008, the overall non-attendance rate for all outpatient clinics in England was found to be approximately 11%, only a 1% reduction compared with 10 years previously (*Health Service Journal*, 2009). This report highlighted that non-attendance rates varied from 5% to 34% according to clinical specialty and geographic area.

Nationally, diabetes constitutes a significant financial burden to the NHS, individuals and society. The direct and indirect cost implication of diabetes in England and Wales for the period of 2010–2011 was calculated to be £23.7 billion (Hex et al, 2012). On an individual level, one consequence of missed appointments by people with long-term conditions is worse health outcomes due to inadequate self-management and the development of avoidable complications.

The diabetes service in Newham, the borough in which this study was based, serves one of the most culturally diverse and deprived areas in the UK (Public Health England, 2015). Historically,

the diabetes outpatient service has had a significant did-not-attend (DNA) rate, with the local borough's diabetes mortality and emergency admission rates being higher than England's average (Healthcare for London, 2009). In 2012, a retrospective audit of attendance was undertaken and demonstrated a yearly DNA rate of 25% (Campbell-Richards and Warburton, 2012). It also highlighted variation in attendance both across and within ethnic groups. Therefore, a qualitative study to understand non-attendance was deemed to be appropriate in order to identify any unmet needs and inform DNA reduction strategies.

Methods

A favourable ethical opinion was granted for the study by the Berkshire B Ethics Committee in March 2013. The study was conducted during the period of May to September 2013 and was funded by a Mary Seacole Development Award for the period 2012/2013.

Design

Focus groups were followed by semi-structured interviews. The primary goal of the focus groups

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Article points

1. In this study, focus groups and semi-structured interviews were conducted to determine the reasons why a high proportion of people with diabetes in the London Borough of Newham failed to attend their clinic appointments.
2. The emergent themes revealed that, while participants were aware of the importance of attending clinic, issues with language and literacy, problems with the organisation and delivery of the diabetes service, difficulties with transport, and costs of travel and missing work often prevented them from attending.
3. Community engagement, improvements in administration and correspondence, and more integrated, community-based service provision are identified as ways to address these issues.

Key words

- Health inequality
- Non-attendance
- Service delivery

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Table 1. Focus group participant details.

	Number willing to attend	Number who attended	Diagnosis (diabetes type)	Gender	Ethnic group
Group 1 (10.30–12.00)	5	2 (plus 1 carer)	Type 2 Type 2	Male Male	Indian Pakistani
Group 2 (16.30–18.00)	No expression of interest				
Group 2 (rescheduled; 13.30–15.00)	4	3	Type 1 Type 1 Type 1	Female Female Male	White British White British Other

Table 2. Interview participant details.

Outpatient attendance profile	African	Bengali	Pakistani	White
Regular attendees	-	3 (2 male, 1 female)	1 (female)	1 (female)
Non-attendees	2 (1 male, 1 female)	2 (both female)	-	1 (female)

was to generate themes to help refine questions for the semi-structured interviews.

Sampling, recruitment and participant characteristics

Focus groups

Focus group participants were identified by doctors and DSNs during the course of clinic consultations over a 3-week period. A list of people who were willing to be contacted was compiled, and these people were contacted by a researcher to confirm their willingness to participate. A total of 19 people were identified for contact; however, only nine expressed an interest in participating. Of these, only five attended the scheduled groups. Their details are given in *Table 1*.

Interviews

Potential participants were identified by clinicians, diabetes database searches and clinic lists. They were then approached based

on the inclusion criteria of ethnicity (African, Bengali, Pakistani or White) and attendance profile (regularly attended or failed to attend appointments and discharged to their GP). During a 3-month period, 10 participants agreed to be interviewed (*Table 2*).

Data collection

Questions asked in the focus groups were designed in response to existing literature on outpatient non-attendance (Gatrad, 2000; Ogeah, 2003; North East Lincolnshire Council, 2004; NHS Newham, 2010). Both focus groups were facilitated by an independent researcher and field notes were documented.

The semi-structured interview questions were refined following analysis of the focus group transcripts. The interviews were conducted by the researcher and tape-recorded. They allowed the interviewees to provide an account of what was important to them and enabled the interviewer to focus on issues that were important to the research. Interviews were facilitated by a bilingual health advocate when required and lasted around 20–40 minutes on average.

Data analysis

All tape-recorded data were transcribed by the researcher as this allowed immersion in the data. The data were examined manually utilising content analysis (Elo and Kyngäs, 2008). Transcripts were read and initial observations documented. Themes were identified from each interview and then collectively examined to determine the relationship between them and the interviewees, both as individuals and as groups of regular appointment attendees or non-attendees.

Results

Focus groups

Four main themes emerged from the focus group discussions as drivers to attendance (*Table 3*, overleaf). Focus group participants were asked “Why do you think people don’t attend appointments?” Five factors were identified that could potentially influence someone’s ability to attend appointments: dependence on others, language problems, lack of knowledge of healthcare, apathy and cultural norms.

Interviews

Attendees

The themes that emerged from participants who regularly attended appointments were similar to those that emerged from the focus group. However, managing multiple illnesses and the cost of attending appointments were additional factors identified as potential barriers to attendance for one participant who had recently been made redundant.

Non-attendees

Seven key themes emerged from interviews with non-attendees. They are outlined in *Table 4* (overleaf).

Discussion

The findings of this study highlight the complex nature of non-attendance, particularly in areas where there is high ethnic diversity and economic deprivation. The task of tackling non-attendance is more challenging when issues of language, literacy, deprivation and health literacy are considered. Existing literature has highlighted difficulties in navigating healthcare systems (Goddard and Smith, 2001; Greenhalgh et al, 2011), which supplement factors such as forgetfulness, apathy, family and work commitments, administrative errors, waiting times, transportation and deprivation (Gatrad, 2000; Ogeah, 2003; Paterson et al, 2010).

Within this study, the geographical location and ability to travel to services were identified as barriers to attendance. This is consistent with existing literature, which has identified service location and transportation access as barriers to attendance. Studies on the impact of geography and transport on access to services have consistently highlighted the impact of spatial decay, whereby the further people are from a service, the less likely they are to attend (Dusheiko et al, 2009). Several participants noted the effort required and challenges faced to get to a location where they could then access public transport. It also became apparent that the geographical distance to a service location is not an accurate indicator of ease of access. The time, effort and cost required to access and utilise public transportation was deemed to have a significant

Table 3. Emergent themes from the focus groups.

Theme	Illustrative quotes
Ownership	<p>“In diabetes, we are our own doctors. You need to be the one to take care of you”</p> <p>“As a child it was my mum’s responsibility but now it’s mine”</p> <p>“Looking after my diabetes is important because I don’t want any complications”</p>
Effective education	<p>“They say no one dies from diabetes but they don’t realise you die from the complications of diabetes”</p> <p>“Coming to the appointment, you find out how to look after yourself and what’s new. There are new things coming all the time so keeping your appointments – you can get new things”</p>
Confidence in specialists	<p>“You need a big mum or dad to look after you and the hospital doctors are good at doing it. We have back-up with the specialist nurse and we can give them a ring”</p> <p>“The hospital doctors are the specialists, so they have all the knowledge”</p> <p>“If you have any questions, you can phone one of the nurses. You’ve always got someone to fall back on”</p>
Fear of complications	<p>“We all try to keep on top of [diabetes] because it stops you from getting the nasty things that go with it. The embarrassment of having a hypo will make me keep appointments...”</p> <p>“My fear is that I will have complications and no one will be there to look after my daughter, so I know it’s important to attend appointments”</p>

impact on one’s willingness or ability to attend appointments. All participants highlighted that services must be easy to access, particularly by public transport. Participants who did not utilise public transport to attend appointments highlighted parking restrictions and insufficient parking around community clinic locations as an inconvenience in terms of both time and cost. One participant, a black African male, stated:

“I drive so I don’t have any problems getting there but it’s when I get there that’s my problem. There’s hardly anywhere to park close by, it’s expensive and if the clinic is late, I’m worried that I will get a ticket.”

This statement illustrated the influence that extrinsic factors, such as over-running clinics and parking restrictions may have on an individual’s willingness or ability to attend appointments.

The financial constraints due to either lost

Table 4. Emergent themes from interviews with non-attendees.

Theme	Illustrative quotes
Language and literacy	<p>"I can't read English or Bengali but when my husband was alive, he took me to all my appointments. He died 8 years ago and now the children tell me when I have an appointment. I don't like to go on my own because of language problems and I get lost"</p> <p>"I get my children to read my letters and they tell me when my appointments are"</p> <p>"It would be good if there was someone you could go to to read your letters and tell you what you need to do"</p>
Family commitment	<p>"I have a disabled daughter to look after. My daughter-in-law helps because she is on maternity leave but she is going back to work in September so then it's just me"</p> <p>"My daughters take turns to go with me but they have their families so it's hard for them too"</p>
Transportation access	<p>"It is hard getting around here [the local area]. I either have to leave almost 2 hours early or take a taxi and I can't afford it"</p> <p>"You have a long walk to get to the bus stop and then you have a long wait for the bus"</p> <p>"My husband gets hospital transport but I have to make my own way. I have kidney problems and can't walk far"</p>
Cost of attendance	<p>"I have a taxi card but I still have to pay £4 one way so when I have to go on my own it costs me £8"</p> <p>"I have to take three buses to go and come back. You might say it's cheaper, but it adds up even with an Oyster [ticketing card]"</p>
Impact of social welfare changes	<p>"I know I have to look after my diabetes, but they stop our benefits 2 month ago. When I have to go to appointments, I take three buses or pay £5 to go and £5 to come back by taxi, so you tell me how easy it is to get to my appointments"</p> <p>"If I couldn't get my Freedom [free travel] Pass when I turn 60, that would have been a problem because I was made redundant"</p> <p>"I have a lot of appointments"</p>
Dissatisfaction with the service	<p>"I was not impressed when I went to my first appointment so I didn't go back"</p> <p>"When you are even a little late, they don't see you but they don't know how hard it is travelling there"</p> <p>"One time I waited 2 hours and then I was in and out"</p>
Inflexibility of services	<p>"Sometimes you have so many appointments in different places, so you have to keep taking time off work"</p> <p>"They could have clinics on a Saturday for people who work"</p> <p>"Do you know how hard it is to try and change your appointment?"</p>

or delayed entitlement to social welfare benefits were a recurrent theme for some participants and were highlighted by both regular attendees and non-attendees. In particular, recent changes made by the Department for Work and Pensions caused great anxiety for several people who were managing multiple illnesses and had scarce or limited resources. This was compounded by the helplessness expressed with regard to their lack of knowledge in seeking appropriate help in order to address the issues of concern.

All participants were asked: "How important is it for you to go to your appointments?" In every instance, a high level of importance was

attached to attending. However, it soon emerged that the ability to attend was influenced by factors other than motivation, perceived risk or perceived seriousness of the disease. A recurrent theme, particularly with non-English-speaking participants, was the devolution of control to family members. In each instance, a high level of importance was attached to attending appointments; however, their knowledge of appointments and ability to attend was dependent firstly on the information being relayed by the respective family member and, secondly, on the relative's ability or willingness to facilitate their attendance. Rose and Harris (2013) have

highlighted the sometimes discordant relationship between self-management practices and the minimisation of diabetes and its impact by family and friends.

All the study's participants with limited English proficiency were highly dependent on relatives to inform them about their appointments and to attend with them. In most instances, the outcome of this deferred decision-making was consistent with the failure to attend appointments. It should also be acknowledged that in such instances, the burden of illness is transferred to family members, who then have to weigh up addressing their own needs against their dependent relative's appointments. This dilemma is compounded when there are multiple illnesses. Transfer of power appeared to be primarily based around language and literacy issues; such instances raise the question of who has true ownership of one's health.

Taking responsibility for one's health has sometime been simplified to comments such as: "If they learn English they will be able to take responsibility for their health." Ownership, however, requires empowerment and a transformational process that is enabled by improved knowledge, skill and confidence.

Perceptions about attending for specialist care were varied and seemed to be dependent on diagnosis. Participants with type 2 diabetes appeared to lack an understanding of the differentiation in appropriateness of GP and specialist care. The consensus by people with type 1 diabetes was that specialist care was best delivered by specialist clinicians as opposed to GPs. In contrast, variable responses were given by people with type 2 diabetes, such as the following:

"When I got the letter saying I was discharged, I phoned the number on the letter and asked for an appointment but didn't get one up to now. So I just thought "I have to look after myself." Since then my GP started me on insulin because my sugar is always high but my sugar is still not good. I was in hospital last Friday because they (my sugars) were too high."

– White female, non-attende
managing multiple illnesses

"I've been with my GP for over 20 years now and he knows everything about me, so yes, I'm happy with him looking after my diabetes."

– Black African male, non-attende

"I was only referred to the hospital by my GP after coming to A&E a few times."

– White male, regular attende

People who regularly attended appointments highlighted education as the means of reducing the incidence of diabetes, improving attendance and overall diabetes care. Jack (2003) emphasised the need for community-based diabetes education as a means of reducing the burden of the condition in communities that are disproportionately affected by it. He elaborated that if educational methodologies are not improved by healthcare providers, there will continue to be minimal patient improvements, and he recommended engaging community partners in order to generate public interest, discussion, ownership, and action around diabetes prevention and control. There was consensus in our study that:

"They [the public] need to realise that diabetes is no joke!"

Other comments included the following:

"They [patients and the public] think you can't die from diabetes but they need to know that you die from complications."

– White female with type 1 diabetes

"Diabetes is like a slow cancer."

– Pakistani male with type 2 diabetes

The inflexibility and a lack of integrated services were raised by several participants. For example:

"Why can't you do clinics in the evening or even on a Saturday?"

"Sometimes you have so many appointments in different places that you forget. I don't mind having a few appointments in the same place on the same day."

During the course of screening potential participants, an administrative issue that appeared to influence outpatient non-attendance was identified. Discordant scheduling of appointments

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could occur, whereby appointments for the DSN were occasionally scheduled in quick succession: sometimes less than 4 hours after a consultant’s appointment. In such instances, non-attendance at DSN appointments occurred, resulting in automatic discharge after two consecutive episodes of non-attendance. Some participants described the letters as confusing, with cancelled appointments being attended and rescheduled appointments being missed.

Limitations of this study

The sample size of the study limits its generalisability; however, the findings are consistent with existing research and highlight additional areas that require further exploration, such as an evaluation of the concept of ownership for one’s health.

Conclusion

The findings of this study highlight the complex nature of non-attendance, particularly in areas where there is high ethnic diversity and economic deprivation. In accordance with Peek et al (2007), the core drivers and barriers to attendance can be categorised into individual, organisational and structural elements. These elements are interdependent and require a cohesive approach in order to successfully address the issues associated with outpatient non-attendance.

What can be done to address these issues?

Addressing these issues is in compliance with the *Public Health Outcomes Framework*, which provides a context from the local to the national level, with an ultimate vision of improving and protecting the nation’s health and well-being, and improving the health of the poorest fastest (DH, 2013). All NHS organisations are tasked with improving efficiency and delivering significant cost savings. The identified issues may appear insurmountable; however, they can be tackled through collaborative working, which will facilitate the transformation of services in a cost-effective manner.

Firstly, engagement with communities can be done at a minimal cost but can produce significant yields in terms of organisations understanding the needs of the local population and delivering “fit-for-purpose” services and/or interventions. Secondly, a review and modification of clinic administrative processes

(scheduling) and outputs (letters) should minimise the administration-related non-attendance. Thirdly, effective engagement by Clinical Commissioning Groups with local health and well-being boards can facilitate meaningful collaboration and strategies in driving forward local health reform. One solution may be the commissioning of integrated specialist services to be delivered within the community at GP premises that are suitably equipped and have the appropriate infrastructure to deliver safe and effective care. ■

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