

Living with diabetes: A qualitative review of minority ethnic groups in a deprived London borough

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This paper aims to explore the experiences of people from a minority ethnic background living with diabetes in a deprived London borough. During the course of a research study by Greenhalgh et al (2011) information was gathered which provided insight into the experiences of black and minority ethnic people with diabetes. A reflective review was conducted based on qualitative data obtained during these focus groups to identify factors that impact on access to diabetes care. The results demonstrated that poor health literacy, socioeconomic deprivation and organisational barriers were key factors in preventing participants from coping with their long-term condition through self-management and engagement with services.

Diabetes mellitus has been shown to be more prevalent in areas of socioeconomic deprivation. Literature about health inequalities has consistently highlighted the negative impact of socioeconomic deprivation on health-seeking behaviours, engagement with services and health outcomes (Diabetes UK, 2006; Harriss and Salway, 2008). Despite this, gaps remain in the understanding of the patient perspective on barriers to empowerment, engagement with and utilisation of services.

This article follows on from earlier research by Greenhalgh et al (2011) and addresses how cultural background is important in encouraging people to understand their condition. It addresses ways in which healthcare professionals can assist people with diabetes by understanding cultural competence.

The study area

Newham is located five miles east of the City of London and has the second most diverse population in the United Kingdom (London Poverty Profiles, 2009). Eighty-six percent of

residents live in areas classed amongst the fifth most deprived areas in England (Association of Public Health Observatories, 2010). According to the 2008 projections from the Greater London Authority, 70% of Newham's population is from black and minority ethnic groups. The largest such group is Black-African, which accounted for 15.8% of the total population in 2010. Asian ethnic groups are also significant in Newham with Indians (11.8%), Pakistanis (10.8%) and Bangladeshis (10.7%) comprising nearly one-third of the borough's population (London Borough of Newham, 2010).

In 2008, the Health Care Commission highlighted that diabetes mortality and emergency admissions rates in Newham were higher than the England average whilst the Yorkshire and Humberside Public Health Observatory (2010) listed Newham as having the third highest estimated total diabetes prevalence in England. Ethnicity is a risk factor in the development of diabetes (Diabetes UK, 2012) and in comparison to the national average, Afro-Caribbean and South Asian communities have

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Article points

1. Diabetes has been shown to be more prevalent in areas of socioeconomic deprivation and deprivation impacts on health-seeking behaviours and utilisation of services.
2. Qualitative data from focus groups of people from minority ethnic groups in a deprived London borough indicate that poor health literacy, socioeconomic deprivation and organisation barriers impact on their ability to cope with their condition.
3. The authors suggest that healthcare professionals should be culturally sensitive and aim to improve services for minority ethnic and deprived groups.

Key words

- Access to care
- Minority ethnic groups
- Socioeconomic deprivation

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a significantly higher prevalence of type 2 diabetes (Diabetes UK, 2010). Type 2 diabetes is up to six times more common in people of South Asian descent and up to three times more common in individuals of Afro-Caribbean descent (Diabetes UK, 2012). Therefore with the higher South Asian and Afro-Caribbean populations and deprivation profile in Newham, it is not surprising that there are higher diabetes-related mortality and morbidity rates compared to the national average.

According to a study undertaken by the Clinical Effectiveness Group (2011), owing to the high prevalence of diabetes within some ethnic groups in Newham, to have diabetes is seen as a “normal” occurrence. This perception may have affected the population’s view of the serious health consequences of this long-term condition. Within the clinical context, poor outcomes have been attributed to factors such as poor compliance and non-attendance. These two factors may be the result of limited English proficiency, poor health literacy and the impact of deprivation on health-seeking behaviours within the local community.

A recent randomised controlled trial conducted within Newham explored and identified themes which were deemed to be the factors influencing day-to-day living with diabetes (Greenhalgh et al, 2011). The main themes identified from this study were health literacy, socioeconomics and organisational factors.

Health literacy

Participants of the Greenhalgh study identified language and literacy as factors impacting on overall health literacy. They reported that both the spoken and written health information provided were sometimes meaningless, even when translated into their own language. Their inability to transform information into action was either due to limited health knowledge or limited linguistic proficiency in either their native language or English and they also felt they were unable to maximise their consultation with their healthcare professional.

It also became apparent that the majority of participants were using the knowledge of how to access healthcare based on their experience of healthcare systems in their country of origin. An example of this was the reluctance to use the bilingual health advocacy service. Furthermore, it emerged that some participants were not aware of this provision and some thought that there was a payment associated with its use. This had a direct impact on participants’ ability or willingness to engage with healthcare professionals. A recent study which explored access to interpreting services in England highlighted that nearly 300 000 adults from the

four main ethnic communities in England and Wales (Indian, Pakistani, Bangladeshi and Chinese) have no functional English to communicate with their health professional (Gill et al 2009).

An example from the Greenhalgh et al (2011) study demonstrates the patient's inability to understand a consultation due to language and literacy factors and insufficient knowledge about support services (see *Example 1*).

Example 1. Language barriers.

A Bengali man had been attending ophthalmic appointments at the hospital and when asked whether he understood why he was attending, he replied "No". He reported that he manages to answer when asked questions but did not really understand what was being said and did not feel able to ask for clarification. This gentleman felt he needed language support but did not know how to get it.

Socioeconomics

Whilst the Department of Health (DH) *National Service Framework for Diabetes* (2001) acknowledged the growing numbers of individuals with diabetes, it cited that the burden of the disease falls disproportionately on individuals from minority ethnic groups and those from socially-excluded groups. Those in the most deprived one-fifth of the population are 1.5 times more likely than average to have diabetes at any given age (DH, 2001). The Improvement and Development Agency (2010a; b) highlighted that the pattern of health inequalities varies widely from community to community. They also reported that Bangladeshi, Pakistani and African people report poorer health outcomes than the white British population.

Some of the participants in the Greenhalgh et al (2011) study had multiple comorbidities due to the nature of their diabetes. A recurring theme during discussions about attending appointments was the need to ration appointments attended due to issues around cost of attendance and implications for work and carers. An example of where a patient needed to make such a choice is shown in *Example 2*.

Organisational barriers

Factors which influence the ease of access and utilisation of healthcare services are multi-dimensional and encompass both personal and organisational elements. Empirical studies which have investigated access and utilisation of services have highlighted the impact of organisational barriers. The

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Example 2. Socioeconomic factors.

At a follow up appointment, a Bengali woman became distraught about attending an upcoming cardiac appointment as her son was not able to accompany her. She stated that he had recently changed jobs and was unable to get time off. She receives £68 per week in benefits and previously spent £40 on a taxi when she attended her last appointment as she does not feel able to travel on public transport on her own. A result of this was her reluctance to attend her cardiac appointment.

concept of porosity and permeability of services as enablers of access to services was explored by Dixon-Woods et al (2005) and one of the findings of this review into vulnerable groups and access to healthcare highlighted that services where there is a high non-attendance rate are less permeable and require evaluation.

In the Greenhalgh et al (2011) study, a significant barrier which was identified as having a negative impact on patients’ willingness to

access services was a perceived imbalance in the power gradient. Patients expressed concerns of not being heard and being ignored, which led to feelings of frustration and disempowerment. A common complaint regarding primary care appointments was that they felt that they could only discuss one issue at each appointment (see *Example 3*).

Patients with limited English proficiency found this to be quite problematic and questioned the value in attending as they could not raise problems of concern. Concerns were also expressed about the gaps in communication between primary and secondary care. They felt the service was not seamless and created anxiety and uncertainty with regards to the provision of treatment recommended.

Many patients suggested the need for assistance from culturally-aware healthcare professionals. They reported that speaking with a person who could speak their language, understood their culture and had the ability to navigate them through the healthcare system would be most beneficial.



Healthcare professionals should use translation services to facilitate healthcare engagement and navigation.

Example 3. Problems in primary care.

A group consisting of Urdu participants collectively expressed frustrations about the difficulty accessing services as the rules are constantly changing. One participant explained that if you manage to get through to the surgery and get an appointment, you can only tell them about one problem, stating "I don't have just diabetes, I have other illnesses that are important."

Recommendations

The *National Service Framework for Diabetes* stipulates that:

"All children, young people and adults with diabetes will receive a service which encourages partnership in decision-making, supports them in managing their diabetes and helps them to adopt and maintain a healthy lifestyle. This will be reflected in an agreed and shared care plan in an appropriate format and language. Where appropriate, parents and carers should be fully engaged in this process." (DH, 2001)

Despite this, regional variability in the delivery of diabetes care remains. A better understanding of factors which influence attendance, compliance and utilisation of services locally is needed.

It is hoped that this article will encourage healthcare professionals to enhance their practice through cultural competence. It has been argued that cultural competence is one of the main ingredients in closing the disparities gap in healthcare (Office of Minority Health, 2005). Furthermore, the Nursing and Midwifery Council (2008) states in *The code: Standards of conduct, performance and ethics for nurses and midwives* that:

"You must demonstrate a personal and professional commitment to equality and diversity."

It is important to note, however, that whilst this awareness is essential for engaging with groups who find it difficult to utilise and access healthcare, in areas where there is huge diversity in ethnicity, it may be difficult for healthcare professionals to be culturally competent in all the diverse groups it serves. Nonetheless, each healthcare professional should strive to be culturally sensitive and aware of their patient's culture.

The results from the Greenhalgh et al (2011) study revealed patients' sense of frustration and feelings of disempowerment. Following on from these results we are advocating the following recommendations to facilitate healthcare professionals' awareness of cultural competence:

“In order to establish a robust and comprehensive approach to diabetes management, future research is required particularly in relation to access and utilisation of services by these groups.”

- The use of bilingual health advocates to facilitate healthcare engagement and navigation.
- Robust care and discharge planning to enable a seamless service.
- Flexible and culturally-sensitive patient education.
- Community engagement to facilitate efficient access and utilisation of services.
- Service re-configuration based on locally-identified needs to minimise the impact of multiple appointments and reduce non-attendance.

The approaches to evaluating and improving diabetes health outcomes are primarily quantitative with a medical model focus. There are still gaps in the qualitative aspects, with regard to factors influencing engagement with services, particularly from groups categorised as hard to reach or vulnerable. In order to establish a robust and comprehensive approach to diabetes management, future research is required particularly in relation to access and utilisation of services by these groups. ■

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