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## Original Research

# What's the worry with diabetes? Learning from the experiences of White European and South Asian people with a new diagnosis of diabetes



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## ABSTRACT

**Aims:** An exploration of diabetes diagnosis from the patient perspective is important for understanding inequalities in access and developing quality care through the diabetes care pathway.

**Methods:** South Asian and White European patients over 16 years with a recent (<1 year) diagnosis of diabetes were recruited from 18 GP practices in three UK locations – Luton, West London and Leicester. A semi-structured qualitative interview was conducted with 47 patients, 28 South Asian and 19 White European. Interview transcripts were analysed thematically and comparisons made between the White and South Asian groups.

**Results:** People expressed a range of emotions at diagnosis. Although many participants were familiar with diabetes through family and friends and were undergoing monitoring for comorbidities, they were surprised and upset to be diagnosed. In contrast, a small number reported how they did not worry about their diabetes diagnosis and others highlighted the different public perceptions, which exist about the seriousness of diabetes in relation to a diagnosis of cancer.

**Conclusions:** Attitudes to diagnosis of diabetes varied on an individual basis and not directly by ethnicity. Practitioners need to be adaptable to work with individuals in order to facilitate access and support diverse populations.

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## 1. Introduction

The rising prevalence of diabetes in the UK [1] is well documented and we know that South Asians populations have higher relative risk of diabetes and kidney complications [2,3] because of genetic, lifestyle or access factors [4,5]. Research to stratify and understand population needs based on ethnicity can help us to understand better the full extent of the challenge of Type 2 diabetes mellitus for those who commission

or provide diabetes care [6,7], particularly as ethnic minorities are predicted to make up 43% of the UK population by 2056 [8]. Previous studies have shown that there can be barriers to healthcare access that relate to ethnicity or culture which culturally competent healthcare providers seek to mitigate [9] in order to provide equitable access and quality in diabetes care [10].

Ethnicity describes a consciousness of belonging to a particular group based on commonality of family origin and culture of shared values and beliefs which is socially

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constructed [11] and which could influence attitudes towards healthcare and self management. Cultural competency is the awareness and application of understanding of how socio-cultural factors interact at multiple levels to influence health [12]. For inequalities in access to be reduced cultural competency of services must increase and research, which explores the experience of care from the patient perspective can help to inform service development.

The combination of quantitative and qualitative data which capture the processes of care and the experience of people who live with this complex chronic disease have the potential to help all stakeholders understand how to maximise access to effective diabetes prevention and management. Policy guidance has increasingly emphasised the fundamental role that people with diabetes play in their own diabetes management [13,14], not purely in terms of increasing patient empowerment and improving experience, but because of the potential for cost savings [15] in the face of increasing diabetes prevalence rates and care costs in the UK of managing diabetes [16,17] and its complications particularly among ethnic minorities [18].

The fact that earlier studies show that by the time they are diagnosed with diabetes, half the people with diabetes already show signs of complications and complications and onset of diabetes may occur 5–6 years and 10 years prior to diagnosis respectively [19,20] highlights the importance of early diagnosis and care around diagnosis for ongoing self management which quality initiatives through the noughties sought to implement [21–23].

The Diabetes Care Pathway Study compared access and experience of diabetes care in White European (WE) and South Asian (SA) groups at three locations in the UK: Leicester, Luton and West London. By using mixed methods and applying a care pathway design to the study we were able to explore and make some evaluation of the impact of the quality initiatives introduced and make some suggestions for whom and how diabetes care could be further improved.

This paper describes patient experience early on in the pathway around the period of diagnosis, which is an important time for people to receive information about the condition in an appropriate and person centred way [21,23,24]. Policy drivers for patient experience work support the use of patient experience data to improve quality of services in the evolving NHS through attention to the key elements of quality, access, cultural sensitivity, shared decision making, information and communication amongst other patient centred objectives [25]. The premise for this element of the larger care pathway study was, that if quality standards to reduce risk, improve identification, promote concordance and deliver care to optimise diabetes control were being achieved, patient's experience data would reflect this.

Patient experiences of diabetes diagnosis and care in 2007, following introduction of quality improvement initiatives: national service frameworks for diabetes and kidney disease and the Quality Outcomes Framework (QOF) during the preceding years are presented and discussed in relation to improving access to quality diabetes care. Broad recommendations are made for NHS diabetes care.

## 2. Methods

The Care Pathway Project was implemented at 3 study sites: Leicester, Luton and West London (Ealing) through 2006 to 2008. The inclusion of study sites was based on the sociodemographics of the local population to enable the inclusion of patients and providers to patients from the predominant South Asian population groups in the UK i.e.: Indian Gujarati; Indian Punjabi; Pakistani, and Bangladeshi.

The overarching study combined audits at two stages in the diabetic renal disease care pathway: at diabetes diagnosis and at referral to specialist renal services in 2004 and 2007, with qualitative interviews with patients and care providers in 2007. This paper concerns the interviews with patients who made up the audit sample at diabetes diagnosis in 2007. The audit element has been previously reported [26,27].

### 2.1. Recruitment and consent

The patients for interview were recruited by participating general practitioners who themselves had been recruited to provide as representative sample as possible in terms of practice population demographics, size, type of practice and QOF achievement scores. The sample selection of GP practices was purposive and pragmatic and the analysis and interpretation of results takes into account study limitations and external validity in relation to sample selection.

It was estimated that up to 20 patients (10 White and 10 South Asian) would be recruited at each site (up to 60 in total), and that this would collectively provide: a representative sample of newly diagnosed patients across the practices, enable at least one patient to be recruited from each participating practice and would be an adequate sample for the proposed analysis [28,29] and fit within the resource limitations of the study.

The project was approved by the NHS Local Research Ethics Committee (LREC). Recruitment took place in 2008. Practice staff conducted a search of practice database to identify patients who fulfilled the inclusion criteria (<16 years, of White European or South Asian ethnicity and diagnosed with T2DM between 1st January and 31st December 2007). All patients who fulfilled the criteria were sent a letter with response slip, patient information sheet and stamped addressed envelope for response. All recruitment paperwork had been approved by the LREC. Those who returned the response slip indicating that they were willing to take part in an interview were followed up with a telephone call from one of the research team (including bilingual researchers as required) to answer any question the potential participant might have and, if the person wished to take part, to arrange the interview.

### 2.2. Data collection

A semi-structured questionnaire schedule was developed specifically for the purpose of this study. This was devised by collaborating researchers (social scientists and clinicians) and comprised a series of questions with prompts covering the following broad areas: diagnosis of diabetes; symptoms; access to and experience of diabetes services; current health;

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