Understanding the role of primary care in the diabetes care pathway: The views of service providers caring for South Asian populations in the UK

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Article points

1. Exploring the experiences of service providers can help in achieving culturally competent services and reducing inequalities in outcomes for South Asian people with diabetes.
2. A semi-structured, qualitative interview of service providers was conducted across three sites (Luton, West London and Leicester).
3. Services had developed in different ways across the three study sites, but a need for a focus of attention on the role of primary care – in particular GPs – was a common theme.

Key words

- Care delivery
- South Asian population

Authors

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Exploring the experiences of service providers who look after South Asian and White European people with diabetes is a necessary step in achieving culturally competent services and in helping to reduce inequalities in outcomes for South Asian people. This qualitative study sought to explore how service providers viewed the progress made in improving access to quality primary care for South Asian and White European people with recently diagnosed diabetes. Service providers were recruited from three UK study sites (Luton, West London and Leicester). A semi-structured qualitative interview was conducted with 14 staff members, and a thematic analysis of the data produced is reported. It was found that services had developed through different approaches at each of the three study sites to improve access for different ethnic groups; however, the role and responsibility of primary care, and in particular GPs, was emphasised. Although national quality improvement initiatives for diabetes have contributed to local service improvements, they have not maximised all opportunities to improve access within primary care. Service provider research can highlight areas that can be developed to improve quality diabetes care across all ethnic groups.

There has been a growing interest in the UK in increasing access to high-quality primary care in order to improve management of long-term conditions such as diabetes. What is less well understood is how these initiatives in primary care have impacted upon the UK's multi-ethnic population, particularly those groups who have a higher risk of diabetes and related complications compared with others.

Previous studies in the UK have identified a greater relative risk for diabetes-related end-stage renal failure in South Asians (those originating from India, Pakistan, Bangladesh and Sri Lanka; Riste et al, 2001; Gholap et al, 2011), and suggested that the quality of healthcare for South Asians is inadequate and compliance poor (Raleigh, 1997; Johnson et al, 2000). There was also a low uptake of hospital-based diabetes services, with some evidence to suggest that South Asians were subsequently referred later for renal care, and more likely to be lost to follow-up (Jeffrey et al, 2002). Moreover, knowledge of diabetes and its complications has been seen to be poor among South Asians (Johnson et al, 2000; Randhawa et al, 2010).

This study explored the concept of patient access to quality primary care – how patients gain access to services and how services are perceived by patients and care providers, the premise being that services need to be relevant and effective if the population is to have access to quality care for improved health outcomes. The concept of access operates on multiple levels (Gulliford et al, 2002). The role of healthcare providers in facilitating access includes the provision of meaningful information communicated in a way that helps to support patients to make decisions about their own care (Department of Health [DH], 2006a). Considering access in the context of primary care services and from the perspective of a diverse sample of providers can help to shed light on where, how and for whom care could be improved early on in the care pathway for diabetic renal disease.

National Service Frameworks for diabetes and renal services were introduced in the UK in 2002 and 2006, respectively. These frameworks provide guidance to healthcare commissioners and providers on the minimum standards of care that should be offered across the UK. Significantly, the frameworks recognised the disparity between ethnic groups and promoted a focus on earlier detection and ethnicity as a risk factor to improve outcomes for diabetic renal disease across different population groups (DH, 2001; 2005). Furthermore, the introduction of the Quality and Outcomes Framework indicators in primary care for diabetes in 2004 and estimated glomerular filtration rate reporting in 2007 were both primary-care based infrastructure developments introduced to improve the quality of care for all people with diabetes (DH, 2003; 2004; 2006b).

Given the policy impetus outlined above, this study sought to explore how service providers viewed the progress made in improving access to quality primary care for South Asian and White European patients with recently diagnosed diabetes. The research described here was one element of a larger study, the diabetic renal disease care pathway study, which explored the concept of patient access to quality care (i.e. how patients gain access to diabetes and renal services and how services are experienced by patients). By combining audit and interview methods the larger project aimed to investigate whether there were differences between the South Asian and White European patient populations in referral rates, indicators for type 2 diabetic renal disease, and care provided, as well as patient attitudes to, and experience of, care at key points through the care pathway.

Methods

The care pathway project was implemented at three 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 from the predominant South Asian population groups in the UK (i.e. Indian Gujarati, Indian Punjabi, Pakistani and Bangladeshi).

The overarching study combined audits and patient interviews at two stages in the diabetic renal disease care pathway – diabetes diagnosis and at referral to specialist renal services – with qualitative interviews with care providers who provide diabetes care prior to referral. The study presented here concerns the latter; the audit at diabetes diagnosis has already been reported in this journal (Wilkinson et al, 2011).

Fourteen service providers were recruited opportunistically through contacts made at each site and interviewed using a semi-structured interview schedule. To be included, interviewees had to be directly involved in the provision of services to people with diabetes, including those recently diagnosed with diabetes. As there has been a shift over time of routine diabetes care from secondary to primary care and in line with a chronic disease care model to provide for the increasing numbers of people with diabetes, the sample included participants from primary and secondary care as well as professionals who work across both delivery areas.

Participant roles in providing care for diabetes patients were:

- Public health manager (one).
- Diabetes specialist nurses (DSNs; three).
- Community dietitian (one).
- Consultant diabetologists (two).
- Diabetes and renal network manager (one).
- Community health promotion worker (one).
- Practice nurses (two).
- GP (one).
- Link worker/community diabetes educator (one).
- Community DSN (one).

A semi-structured questionnaire had been developed specifically for the purpose of this study. This was devised by collaborating researchers (social scientists and clinicians). Both the

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3. Interviewees were directly involved in the provision of diabetes services to people with diabetes early in the diabetic renal disease care pathway.

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participant information sheet and the preamble to the interview asked participants to recount their experience in their own words; the interview schedule was intended to be used as a guide and to ensure that the main areas were covered during the course of the dialogue.

One-to-one interviews were conducted by researchers at the participant's workplace. They lasted approximately 1 hour and were tape recorded. The resulting recordings were transcribed into documents on Microsoft® Word (Microsoft Corporation, Redmond, WA, USA).

The interviews explored a range of areas in diabetes care – perceived barriers for South Asians in accessing services, perceived barriers to treatment adherence among South Asians, and initiatives they may have tried in improving access to services among South Asians. Interviews explored whether the issues they raised differed from or resonated with their experiences with patients of White European ethnicity.

Analysis

Interview transcripts were repeatedly read through, an initial framework of key themes (initial thematic categories) was formulated, and interviews were analysed using these themes as well as others that emerged. The thematic approach to analysis is a widely used process in the analysis of qualitative data (Braun and Clarke, 2006; Ritchie and Lewis, 2008) and was used in this research to identify a conceptual framework of themes and sub-themes which relate to the access and quality of healthcare. Analysis of data from some of these themes and sub-themes forms the basis of the following results.

Results

Emerging themes related to participants' observations of access at different levels (individual interactions with patients, the pathway and service as a whole, and service provider skills as a means of access). The results discussed here have been selected to reflect the multi-level viewpoint that participants provided.

All participants referred to the role that primary care and, specifically, GPs have to play in the patient pathway and identifying where there was scope for improvement.

> *"… and I don't think they understand public health and health promotion, it's not about doing – giving just leaflets, or doing some admin work… it's more than that, it's looking [at] evidence-based information, it's actually about training… So they don't think about those things; I think GPs don't like capturing all those patients; if they don't get paid for that they won't do it"* (Respondent [R] 14).

> *"What we need, seriously, is making sure that there is a current, holistic overview of what's happening with the patients. The GP must obviously find it extremely difficult; he sends the patient to me; I send reports to him on how their lifestyle and diet is. The DSNs must be sent information about how their diabetes management overall is, because of compliance of drugs and so forth and then there'll be biochemistry – he'll have to come up, translate all that information, say whether this patient's got a risk of renal problems and issues, or – you know, that must be an enormous task for because it's quite challenging to get an overall picture of the state of a diabetic patient"* (R12).

Other participants observed that whilst policy initiatives to increase the level of diabetes care managed in general practices had resulted in few referrals to diabetes specialists, there were still people who did not appear to have effective diabetes care.

> *"And, you know, there are some GPs that are brilliant out there, absolutely wonderful, and there are some that, you know, they're not so good and I am not sure that those patients – well people are not being referred and this drive not to refer people, sometimes I think is a false economy, that there are patients that we need to – even if it's just a couple of visits just to straighten them out and then they can be put back into the community with 'pastoral care'"* (R13).

> *"So, and we also seem to realise that now there are more patients who come in for acute medical surgical reasons, who are under the GP only for the diabetes, who actually have extremely poor diabetes control. Obviously that complicates their*

> *illness; while they're here we pick them up and we therefore get them into our system thereafter, not because the GPs refer them, because they come into hospital with something often unrelated to their diabetes"* (R10).

> *"… and we've just found that, you know, patients could be diagnosed x number of years, but when they come up there'll still be* [inaudible] *but nobody told them that. That's a good thing, you know, with patients coming time and time again and, you know, you may be the one that told them it in the first place…"* (R11).

There was also a concern raised about the quality of checks within primary care:

> *"… But we, I think that what we don't understand is actually where is quality behind that to make sure what's recorded in terms of practice, day-to-day first, is actually what is the quality of that, and that's something we've always had a concern about in* [X]*, which is why what we're trying to look at is – do we have a competent workforce, not so much the who but it's do we have a competent workforce to enable them to understand – 'ah, so that's the new thinking in ethnic education, this is what's new in diabetes, this is what's new wherever'. And I think we've always, always driven education to healthcare professionals; that's been top priority"* (R9).

> *"… but of course there's a huge variation of standard and skill levels and knowledge levels and the services provided in primary care. We do have a community DSN in* [X] *but not* [X] *who has done a lot of facilitation… but there are some surgeries who, first of all, it's very difficult for her to get in due to their reluctance to have someone from outside come in potentially criticising everything you do. So it's been difficult, I mean, she has got some information on background, sort of background information on skill levels at the individual surgeries, but again it's never been properly presented and discussed at a forum, where we can therefore use the information to plan the next step in the strategy"* (R10).

Services had approached the development of diabetes care and access in different ways at the three study sites. At one site, an overarching public-health approach operated through the Primary Care Trust-led local consultative committee was supporting a range of local services working with people with diabetes alongside an innovative GP-led community health promotion project. At a second site, there was a strong base in diabetes research, including structured patient education, originating from the university and secondary care, which had developed good research collaborations with primary care and facilitated local guideline development and implementation, as well as a comprehensive website. The third site had taken a predominantly practitioner-led approach and had developed an innovative programme of bilingual patient education in primary care.

On the first two sites, the locally developed approaches appeared to be able to harness or have become integrated and have effects wider than the initiatives themselves, whereas the practitioner-led approach, in the absence of a locality-wide strategy, struggled to engage GP practices across the third area.

> *"The GPs have been very good working with us, because of the new [General Medical Services] links. So the only part we are missing is health promotion, so whether it comes through the session here on Saturday, or whether it's done there, health promotion is being done… There are some places we are doing very good work. You can see when patients come we say 'who's your GP', they are better monitored"* (R6).

> *"The practices who are involved and… those patients who are involved [in research] – there's no doubt they do actually influence what else goes on in that practice. And if you have a practice nurse who is very engaged, in a sense, in some of that research, then the outcomes are going to be far better than some practices where – mmm, can't seem to keep my head above water here…"* (R9).

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Discussion

Service providers described the ways that primary care services had developed and adapted to address some of these barriers, such as employing trained diabetes support workers and the use of peer educators to raise awareness of the importance of diabetes self-management, diagnosis and structured education in different South Asian languages. The role of primary care – in particular GPs – was emphasised as requiring particular attention.

The changes that had been implemented in primary care during the previous few years had served to focus attention on diabetes as a major concern for GPs, increase the levels of monitoring by GP practices and reduce referrals to specialist diabetes care. Although the service providers we spoke to also recognised that these changes were positive improvements, they felt that they had not managed to raise standards across all practices. There were also concerns about how far such quality improvements had translated into the quality of practical care with patients, for example in the quality of the checks conducted and the level of GP involvement in preventative work, particularly with people with diabetes who were more difficult to engage with for reasons mentioned earlier.

Other studies have reported that quality improvement initiatives in primary care have improved processes and intermediate outcome measures of quality (Khunti et al, 2007), and that these have had a positive impact on care across different ethnic groups (Millett et al, 2009). However, misgivings have also been expressed that "pay for performance" in primary care has limitations (Sigfrid et al, 2006; Mangin and Troop, 2007; Gadsby, 2009), and is not able to tackle continuing disparities in management, control and complication outcomes of diabetes (Millett et al, 2007), because achievement of targets does not necessarily translate into quality care and better outcomes for all people with diabetes.

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Our findings, together with the ongoing emphasis on primary care's role to deliver on the management and support of people living with chronic conditions (DH, 2012), suggest that practitioner research that can identify facilitators and barriers to the delivery of quality diabetes care will be valuable to inform service development, and improve access to quality care. As the focus of this study was access for the South Asian population to diabetes care, this work has been able to shed some light on delivering culturally competent care in the diabetic renal disease care pathway. A discussion of the basic concepts involved has been published previously (Wilkinson and Randhawa, 2012).

The different approaches to diabetes care that had developed at each site had been most effective where there had been a combination of a strategic, "macro level" approach with a locally developed initiative that had grown out of local expertise and interest. On one site where an overarching strategy did not feature, the innovative service-led programme appeared to have more difficulty in getting access and engaging with all practices and therefore their populations. As self-care in diabetes management involves medication, education, monitoring and support, the relationships between strategies, organisations and infrastructures that underpin patient access should be considered in service improvement.

Conclusion

Services reported their understanding of the needs of different patient groups in relation to access, gave examples of the approaches taken locally and identified primary care – in particular the role of GPs – in relation to quality and prevention as requiring more attention to improve access. Service provider research will be valuable for the development of quality diabetes care through new local NHS structures. ■

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> ***"Service provider research will be valuable for the development of quality diabetes care through new local NHS structures."***