

Institution: Anglia Ruskin University

Unit of Assessment: Allied Health Professions, Dentistry, Nursing and Pharmacy

Title of case study: Case Study B. Improved Eye and Healthcare for diabetic patients of South Asian origin

1. Summary of the impact

Research led by **Pardhan** has enhanced the healthcare offered to diabetic patients of South Asian origin in the UK and overseas (Pakistan, East Africa). Prevalence of diabetes within this ethnic group is six times higher than in Caucasians. Our research into this group, which demonstrated an increased risk of sight-threatening eye disease and poor engagement with screening/treatment regimes, has impacted upon both patients and healthcare practitioners. Ophthalmologists, general practitioners and other clinicians have used our findings to target various physiological and cultural factors that influence diabetic control and eye health in the South Asian population.

Our research also provided the underpinning data that informed reports commissioned by the Royal National Institute of Blind People (RNIB). These reports demonstrate the increased prevalence of eye problems in patients of South Asian origin, and highlight the barriers that affect patients' access to primary and secondary eye-care across the UK. The reports evaluate the effectiveness of current management, and suggest strategies to improve the eye health of this group of patients.

These reports have led directly to the creation of dedicated community-based eye-care programmes. Funded by the Royal National Institute of Blind People (£400,000) and Innovation, Excellence and Strategic Development Fund (Department of Health), the programmes are designed to reduce diabeticrelated complications through improved self care by patients in Bradford and Glasgow, regions that have significant Asian diabetic populations.

2. Underpinning research

The ground-breaking research was led by **Pardhan** (Professor, Anglia Ruskin University, 2001present) as part of her wider research interest into the factors that influence diabetic eye changes. Her current research project in diabetes and its complications is supported by NHS Cambridgeshire NIHR Research Capability Funding [1], and employs a full-time postdoctoral Research Fellow (**Scarfe**). She also collaborates with the Aga-Khan Hospital, Nairobi, to investigate the impact of lifestyle on diabetic complications in South Asian patients.

The research first began at the University of Bradford (1997) when **Pardhan** was a Senior Lecturer. Working with Mahomed (Bradford Royal Infirmary), she designed the study and Mahomed provided access to patients. After her appointment at Anglia Ruskin University (2001), she continued this research and completed further data collection, data analysis, modelling (in collaboration with Gilchrist, Bradford University), leading to several publications [2-5].

The prevalence of diabetes in England alone is predicted to increase by 47% by 2025 and this will inevitably lead to a broad range of complications, including diabetic eye changes. A comparison of the clinical and demographic characteristics of patients on the Bradford low vision register [2] demonstrated that diabetic eye complications caused 3.5 times more blind registrations of patients of South Asian origin compared to Caucasians. A subsequent large-scale study carried out in Bradford (500 patients) provided evidence that these patients had significantly higher prevalence of sight-threatening retinopathy compared to Caucasians [3]. Statistical analysis showed that Asians were presenting with levels of eye disease comparable to those of the Caucasian cohort who were either 12 ½ years older, or had had diabetes for 12 ½ years longer. This worrying finding highlighted the urgent need for improved eye-care for Asian diabetic patients in the UK.

Whilst it is not possible to change the duration of diabetes or the age of the patients, other parameters that also influence long-term eye health outcomes include diabetic control and its management. Subsequent research on the same patients [4, 5] demonstrated that there were key lifestyle differences between Asians and Caucasians, including poor awareness of the importance of a nutritionally balanced diet, and the need for regular exercise. Specifically, South Asian patients exhibited a significantly reduced understanding of the nutritional constitution of their diet, and showed less concern



when engaging in activities that could affect the 'control' of diabetes (e.g., resulting as a consequence of cultural and religious activities such as fasting).

The South Asian group also demonstrated significantly lower awareness of the importance of diabetic control and compliance with treatment regimes, as well as less concern at missing clinical appointments. The research highlighted the need for improved diabetic control and surveillance in this group and emphasised the need for improved understanding of diabetic complications, early screening, health management practices (both clinical and patient-led) and patient engagement. We concluded that there is a clear need to improve patient engagement in self-management, better education to improve lifestyle choices and to ensure attendance at regular eye examinations. The research elevated the profile of the ethnic disparity in eye health which, if not addressed, would lead to enormous on-going treatment costs.

3. References to the research

Grants:

1. **Pardhan S**, (2012). The impact of diabetic retinopathy and neuropathy on patients' functional disability. NHS Cambridgeshire NIHR Research Capability Funding, £49,000.

Journal Articles:

- 2. **Pardhan S**, Mahomed I. (2002). The clinical characteristics of Patients on the Bradford's Low Vision Register. *Eye*, **16**(5), 572-576, doi:<u>10.1038/sj.eye.6700164</u>.
- 3. **Pardhan S,** Gilchrist J, Mahomed I. (2004). Impact of age and duration on sight threatening retinopathy in South Asians and Caucasians attending a diabetic clinic. *Eye*, **18**(3), 233-240, doi:10.1038/sj.eye.6700629.
- 4. **Pardhan S**, Mahomed I. (2004). Knowledge, self-help and socio-economic factors in South Asian and Caucasian patients. *Eye*, **18**(5), 509-513, doi:<u>10.1038/sj.eye.6700680</u>.
- 5. **Pardhan S,** Mahomed I. (2007). Risk factors associated with diabetic retinopathy in South Asian patients. *Journal of Modern Optics*, **54**(9), 1289-1298, doi:10.1080/09500340600855270

4. Details of the impact

A. Improved management and care regimes offered by clinicians in the UK and overseas:

Our research provides evidence of higher levels of sight-threatening diabetic eye changes in patients of South Asian origin compared to Caucasians. Furthermore, we highlighted several lifestyle and 'non clinical factors' that contribute to these higher levels of sight-threatening eye disease in South Asians. Asians showed low levels of awareness of the need for good control of diabetes: poor lifestyle management; language problems; lack of awareness of the importance of attending diabetic screening appointments.

Dissemination of specific and relevant research results to senior diabetic healthcare consultants in Pakistan, East Africa and the UK has increased the awareness of the various 'non-clinical' factors that influence sight-threatening diabetic complications in patients of South Asian origin.

In Pakistan, the research has led to recommendations by the South Asian Federation of Endocrine Societies [1] to clinicians offering diabetic care in various clinics and hospitals in Karachi. These recommendations have led to enhanced care management delivered to patients (July 2013). The research has also informed the management of diabetic patients in Bugando Medical Centre (Mwanza Tanzania), a teaching hospital for the western zones of Tanzania [2] (June 2013). Serving a population of 13 million people, the Centre is a referral centre for tertiary specialist care for six regions, including Mwanza, Mara, Kagera, Shinyanga, Tabora and Kigoma. In addition, a primary care centre in Mwanza (Tanzania), which has recently set up a new diabetic clinic, uses our research findings to impress upon their patients the importance of attending regular clinics, eating a balanced and nutritious diet, and adhering to prescribed medication (May 2013).

In the UK, consultant ophthalmologists [3] (June 2013) and general practitioners [4] (June 2013)



working in areas with relatively large populations of South Asian descent (and where national statistics highlight that blindness due to diabetes is high) have employed specific components of our research to enhance the care they provide to their patients. For example, the strategy to involve community elders and seek their support in overcoming language barriers has resulted in improved patient engagement which will lead to improved eye-health.

B. Increasing awareness through commissioned reports leading to improved care in the community:

Our research provided the underpinning data for commissioned reports that have led directly to community-based Eye Health Engagement Projects:

(a) RNIB-commissioned report entitled "*A review of evidence to evaluate effectiveness of intervention strategies to address inequalities in health care*" [5]. Using our research it highlights the barriers that affect access by ethnic minority patients to primary and secondary eye-care across the UK, and suggests strategies to reduce this inequality.

(b) Public Health Action Support Team (PHAST) "*Eye Care in the UK: Epidemiology, Intervention and Ethnicity*" [6] is part of a wider Eye Care Needs Assessment for NHS Tower Hamlets (and reported by the RNIB). The report highlights the increased prevalence of eye problems in patients of South Asian origin. It evaluates the effectiveness of current strategies employed to reduce inequalities in eye-health in ethnic minorities, and proposes remedial measures including targeted screening and holistic assessments.

These reports led directly to the development of community-based Eye Health Engagement Projects in Glasgow [7] (2012) and Bradford [8] (2012) which have significantly high populations of diabetic patients of South Asian origin. These projects have been supported by substantial investment from the RNIB (£300,000 for the Glasgow project, and £100,000 for the Bradford project). The Bradford project also received funding from the Innovation, Excellence and Strategic Development Fund (IESD) from the Department of Health.

The Eye Health Engagement Projects employ a series of strategic interventions which address some of the main findings of our research. More specifically they are designed to increase: (a) healthcare uptake, treatment and compliance; (b) the uptake of eye examinations and diabetic retinopathy screening; (c) the understanding of the need for eye examinations; (d) the understanding of eye health and its relationship to diabetes; (e) community engagement and raising awareness via eye-health champions.

The Glasgow community-based project, which has targeted the Pakistani population, has focused on raising the awareness and understanding of diabetic eye health. This has involved making sure that health professionals provide consistent information, and that this information is shared with the community via eye-health volunteers and champions. In Bradford, the community project has involved various strategies, including the use of SMS 'text' reminders from doctors' surgeries, telephone reminders by a bilingual person, improved community education and awareness programmes via community and religious groups, and the use of a 'personal folder' to support self care. The folder, trialled on 500 people, is designed to help individuals keep appointments, set goals/targets and manage their medication regime effectively.

Further impact is evidenced via the RNIB who have been approached by care commissioning groups (in Bradford City and Bradford District) who wish to promote and support the use of the 'self care personal folder' initiative more widely [8]. It is anticipated that further clinical outcomes will arise as these projects mature.

C. Raising the understanding, at government level, of factors that affect the health of two million South Asians living in the UK:

Our research informed a significant joint report written by Diabetes UK and the South Asian Health Foundation [9] that was launched at a Parliamentary reception hosted by Keith Vaz, MP (June 2009) to raise the awareness of the specific health risks facing South Asians. The report recommended



priorities for future interventions and research in diabetes and its complications in patients of South Asian origin, resulting in a number of projects, commissioned by the Diabetic UK to address these.

D. Informing healthcare commissioners:

Our research informed a PCT Health Equality Audit which made recommendations (Southampton, Hampshire, Isle of Wight, Portsmouth City) for healthcare commissioners to target health inequalities in ethnic minorities [10] (2010). The audit explored whether healthcare services and other resources are distributed equitably to meet the health needs of different ethnic groups. The report identified factors that predict who is most at risk of diabetic retinopathy and those who were less able to access diabetic retinal screening. It recommended policies and procedures to reduce the inequality in health in ethnic minority patients, resulting in greater commissioner awareness of how to improve access for patient groups who are not currently being served effectively, and for whom the clinical prognosis has historically been particularly poor. These recommendations were presented to healthcare commissioners and planners in Southampton City (February 2012). As a result, the Public Health Information team (Southampton City, February 2012) recommended that data across the different GP practices should be analysed and compared to the average for the City, in order to highlight any potential differences and identify any inconsistencies between need and service access.

5. Sources to corroborate the impact

- A. Improved management and care regimes offered by clinicians in the UK and overseas:
- 1. [Testimony] from Vice President: South Asian Federation of Endocrine Societies and Immediate Past President: Pakistan Endocrine Society (July 2013)
- 2. [Testimony] from a Medical Doctor in Internal Medicine, Bugando Medical Centre, Mwanza (June 2013)
- 3. [Testimony] from Ophthalmology Clinical Lead in Diabetes in Peterborough NHS Trust (June 2013)
- 4. [Testimony] from a Primary Care General Practitioner in Northampton (June 2013)

B. Increasing awareness of health risks leading to improved care in the community:

- [Report] Johnson M, Cross V, O Scase M, Szczepura A, Clay D, Hubbard W, Claringbull K, Simkiss P, Leamon S. (2012). A review of evidence to evaluate effectiveness of intervention strategies to address inequalities in eye health care. Royal National Institute of Blind People (RNIB). http://www.rnib.org.uk/aboutus/research/reports/prevention/pages/evaluation_interventions.aspx.
- [Report] O'Donnel J. (2009). Eye care in the UK: Epidemiology, Intervention and Ethnicity. Royal National Institute of Blind People. As part of a wider Eye Care Needs Assessment for NHS Tower Hamlets, carried out by a team supplied by the Public Health Action Support Team CIC (PHAST). Hyperlink: <u>http://www.rnib.org.uk/aboutus/Research/reports/2010/Eye_care_uk.doc</u> (*can be supplied by the HEI upon request*)
- [Report] Thompson L, and Burton P. (2012). Glasgow Eye Health Community Engagement Project Eye Health Equity Profile. NHS Greater Glasgow & Clyde. Hyperlink: <u>http://library.nhsggc.org.uk/mediaAssets/PHRU/Glasgow%20Eye%20Health%20Equity%20Profile</u> <u>%20-%20FINAL%2012Jan2011.doc</u>.
- 8. [Testimony] Public Health Development Manager [2013]. RNIB, confirming that the RNIB report led directly to the development of the Community based projects in Glasgow and Bradford in 2012

C. Raising the understanding, at government level, of factors that affect the health of two million South Asians living in the UK:

9. [Report] Khunti K, Kumar S, Brodie J. (2009). Diabetes UK and South Asian Health Foundation recommendations on diabetes research priorities for British South Asian, hyperlink: http://www.diabetes.org.uk/upload/Reports/South_Asian_report.pdf.

D. Informing healthcare commissioners:

10. [Health Audit Report] Fraser S, Edwards L. (2010). Health Equity Audit - Diabetic Retinopathy Screening. Southampton City, Hampshire, Isle of Wight and Portsmouth City PCTs. hyperlink: http://www.portsmouth.gov.uk/media/API_STR_JSNA_BURD_DBTES_EQAUDIT.pdf.