DISCRIMINATORY CARE AND SOUTH ASIAN PATIENTS WITH CHRONIC GASTROINTESTINAL DISEASES

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A thesis submitted in partial fulfilment of the requirements of Staffordshire University for the award of the degree of Doctor of Philosophy Based upon Published Work

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I would like to thank Professor Peter Kevern for his invaluable advice and guidance in the development of this submission.

Abstract:

The research in this dissertation has shown widespread and prolonged discrimination in provision of healthcare to South Asian patients with chronic gastrointestinal diseases. The data, which forms the basis for the analysis, were collected using different techniques, in different places and at different times. The consistency of the findings reinforces their reliability. In the initial study, a cohort of newly diagnosed patients with ulcerative colitis was assessed over a 10-year period. South Asian patients were less likely to see a consultant, underwent less investigations and were more likely to be discharged. Subsequent studies showed South Asian patients with Crohn's disease were less likely to receive expensive biologic therapies. These studies reviewed treatment registers and data generated from Freedom of Information requests. In the case of achalasia, the first study of its incidence in the South Asian community showed it to be of comparable frequency to White British people. The first meta-analysis of cancer frequency demonstrated the risk to increase progressively with time, although no specific information for the South Asian community could be extracted. However, a review of treatment modalities demonstrated South Asians with achalasia were significantly more likely to receive novel treatments given by practitioners on the early part of their learning curve. Despite objective evidence for substandard care given to South Asian patients, trusts and associated monitoring bodies, where this happened, denied the reality of the findings and reported no appropriate adjustments. National bodies with statutory responsibility for ensuring equitable care could provide no examples of actions which they had taken to remedy such situations. A review of legal options through which poorer care for South Asian patients could be addressed failed to identify any effective remedies and proposed that the only effective option available was through the tort of negligence. Potential methods of improving this situation are discussed.

Statement concerning where and when the research submitted for consideration of a PhD by Prior Publication was undertaken.

The research which forms the basis for this submission was undertaken between 2005 and 2020. There were times during this period when research activities by myself were limited by clinical commitments and in preparation for clinical examinations, namely membership and specialty examinations of the Royal College of Physicians and also full-time training for the Bar.

The work was based at University Hospitals of Leicester NHS Trust, but during this period I worked in many hospitals in the East Midlands, NorthWest Anglia Trust and Lincolnshire.

At no time during this period did I hold a contract with a university.

Affifa Farrukh
7/7/2020

Statement concerning submission of material for consideration of a PhD by Prior Publication.

The material which is submitted for consideration of a PhD by Prior Publication to Staffordshire University has not been and is not being submitted in respect of another research degree at this or any other University.

Affifa Farrukh
7/7/2020

During discussions about the nature and content of my submission linked to the prima facie case the review:

Farrukh, A. (2020) ‘What are the legal mechanisms for seeking solutions to disparities in the delivery of care in the NHS and where does liability lie?’ *Denning Law Journal* **32,** pp. 51 - 86

was added to the publication list as it explains potential routes for dealing with discrimination in delivery of care. The concept was addressed in a submission, which formed part of my LLM on the Bar Professional Training Course at Nottingham Trent University. However, the published paper is a significantly more detailed and extensive review of the topic. It contained additional and new material.

Affifa Farrukh 24/4/2021

Statements concerning contribution by Affifa Farrukh to the Publications submitted for consideration of a PhD by Prior Publication.

The material which is submitted for consideration of a PhD by Prior Publication to Staffordshire University is work which was conducted by myself. Throughout the work submitted, I formulated the ideas behind the research, carried out the collection of the data, analysed the results collected, wrote the paper and submitted it to academic journals and made subsequent revisions. An exception was in the metanalysis of cancer risk in achalasia, where Dr Clare Gillies analysed the data, which I provided. Review publications were conceived by myself, the literature search and analysis of papers performed by me, the subsequent review written by me and revised following critical comments by Professor John Mayberry. I submitted the papers to academic journals and made any subsequent changes. In summary, the work that has been presented is essentially my work, with the role of the co-authors being limited to critical comments on the paper prior to submission to academic journals, with the exception of the work of Dr Clare Gillies discussed above.

Affifa Farrukh

1/5/2021

Below I have attached a list of papers together with the comments of my co-authors. These data were collected during the Covid 19 epidemic and I have pasted the comments of each co-author beneath each paper. However, I have asked Professor Mayberry, who has been a co-author on all but one paper to make a general comment.

Statement by Professor John Mayberry DSc MD LLM MSc FRCP FRCPI

Affifa Farrukh first came to work with me in 2004 from Pakistan as a clinical attachment to learn endoscopy. From the first, she was keen and enthusiastic, involving herself in all aspects of clinical work. All team members were encouraged to develop a research interest and appropriate related skills. This led to an early original publication on the epidemiology of achalasia in the South Asian population of Leicester. This was the first and only migrant study of this disease. From that first study she took the initiative, discussing concepts and how she would collect data, going out and collecting the data itself and writing drafts of the papers. Over the years my contributions became less and less, largely involving discussions about her ideas, asking difficult questions and suggesting suitable journals. I would describe her overall contribution to the papers we have published together as being greater than 95%.

John Francis Mayberry

Publications linked to submission for a PhD:

1. Farrukh, A. and Mayberry, J.F. (2021)
   ‘Original observational study on disparate treatments for achalasia experienced by patients of white British and South Asian ethnicity.’
   Annals of Esophagus doi: 10.21037/aoe-20-72:
   http://dx.doi.org/10.21037/aoe-20-72

2. Farrukh, A. and Mayberry, J.F. (2020)
   ‘Apparent disparities in hospital admission and biologic use in the management of inflammatory bowel disease between 2014 – 2018 in some Black and Ethnic Minority (BEM) populations in England.’
   Gastrointestinal Disorders **2(2),** pp. 141 – 151
3. Farrukh, A. and Mayberry, J.F. (2019)
   ‘Does the failure to provide equitable access to treatment lead to action by NHS organisations? The case of biologics for South Asians with inflammatory bowel disease.’
   Denning Law Journal **31,** pp. 77 – 91
4. Farrukh, A. and Mayberry, J.F. (2019)
   ‘Evidences of differences and discrimination in the delivery of care: colorectal screening in healthy people and in the care and surveillance of patients with inflammatory bowel disease.’
   Gastrointestinal Disorders **1(2),** pp. 253 – 260
5. Farrukh, A. and Mayberry, J.F. (2019)
   ‘Inflammatory bowel disease and the South Asian diaspora.’
   JGH Open **3(5),** pp. 358 – 360
6. Farrukh, A. and Mayberry, J.F. (2016)
   ‘Patients with ulcerative colitis from diverse populations: the Leicester Experience.’
   Medico Legal Journal **84 (1),** pp. 31 – 35

7. Farrukh, A. and Mayberry, J. (2015)
   ‘Ethnic variations in the provision of biologic therapy for Crohn’s Disease: A Freedom of Information Study.’
   Medico-Legal Journal **83(2),** pp. 104 – 108

8. Farrukh, A. and Mayberry, J. (2015)

‘Apparent discrimination in the provision of biologic therapy to patients with Crohn's Disease according to ethnicity.’
Public Health **129(5),** pp. 460 - 464

9. Mayberry, J.F. and Farrukh, A. (2012)
   ‘Gastroenterology and the provision of care to Panjabi patients in the UK.’
   Frontline Gastroenterology **3(3),** pp.191-198

Other co-authors:

The following 3 papers included additional authors. I have incorporated statements from 3 of the 4 co-authors as to the level of my contribution. This was obtained in May 2020. I have been unable to obtain a statement from Professor Keith Abrams, who was the supervisor of Dr Clare Gillies at the time of the study.

10. Gillies, C.L., Farrukh, A., Abrams, K.R. and Mayberry, J.F. (2019)
    ‘Risk of oesophageal cancer in achalasia cardia: A meta-analysis.’
    JGH Open **3(3),** pp. 196 - 200

11. Farrukh, A., Sayeed, S, and Mayberry, J.F. (2014)
    Oral health and the provision of care to Panjabi patients in the UK
    Dental Update **41(7),** pp. 629 – 636
12. Farrukh, A., DeCaestecker, J. and Mayberry, J.F. (2008)
    ‘An epidemiological study of achalasia among the South Asian population of Leicester, 1986-2005.’
    Dysphagia **23 (2),** pp.161-4

Statement of Contribution

Gillies CL, Farrukh A, Abrams KR & Mayberry JF (2019)
Risk of oesophageal cancer in achalasia cardia: A meta-analysis.
JGH Open https://doi.org/10.1002/jgh3.12132

Affifa Farrukh helped develop the search strategy, and was the primary researcher leading on the selection of papers for inclusion from the search results. She also extracted the data to form the basis for the meta-analysis, which I conducted. Affifa also contributed significantly to the writing of the paper. Her contribution to the paper can be assessed as 35%.

Clare Gillies

Dr Clare Gillies Date 12/05/20

Statement of Contribution

Farrukh A, Sayeed S & Mayberry JF (2014)
Oral health and the provision of care to Panjabi patients in the UK
Dental Update **41:** 629 – 636

Affifa Farrukh designed the study, collected the data, analysed it and wrote the paper. My role was as a guide and critical commentator. Her contribution to the paper can be assessed as 95%.

11th May 2020

Dr Saad Sayeed Date

Statement of Contribution

Farrukh A, DeCaestecker J, Mayberry JF (2008)
An epidemiological study of achalasia among the South Asian population of Leicester, 1986-2005.
Dysphagia **23:** 161-4

Affifa Farrukh designed the study, collected the data, analysed it and wrote the paper. My role was as a guide and critical commentator. Her contribution to the paper can be assessed as 90 %.

Professor John De Caestecker Date 20/05/2020

Index:

1. Introduction:

> "Of all the forms of inequality, injustice in health is the most shocking and inhuman." (Martin Luther King Jr, 1966) (Munro, 2016)

This chapter will deal with the recognition of disparate care for black and ethnic minority (BEM) communities in the UK. It will consider the approach to equality of care developed within the National Health Service (NHS) and the effectiveness of monitoring by statutory government bodies. Documented examples of disparate care in various diseases in the UK will be noted and the rationale for studies in Leicester explained, together with the choice of gastrointestinal diseases as an exemplar.

Issues around equality of access to healthcare had been of concern in the UK since the time of the Webbs. On 6 March 1911 Beatrice Webb wrote in her diary:

> "What we are trying to achieve is to direct the sickness insurance scheme into a big reconstruction of public health"

Their work on this reconstruction, together with that of other social reformers, led to the foundation of the National Health Service (NHS) on 5 July 1948 through the determined efforts of Nye Bevan. In 1958, during a debate in the House of Commons, he spoke of its purpose:

> "Many people have died and many have suffered not because the knowledge was not there, but because they did not have access to it. To all the suffering which attends illness, there was always added the bitterness that, if the poor could have had access to the knowledge available, they might have been saved, or at least, might have been

> helped. It was this situation that the National Health Service was intended to put right.” (Bevan, 1958)

This concept of free and open access to healthcare in the United Kingdom was a basic principle of the NHS.

Ethnicity and Healthcare in the UK:

However, thirty years after the foundation of the NHS, a Royal Commission on the NHS was of the view that there were special demands from “an aged, *migrant* or homeless population” (Merrison, 1979). The Commission went on to say:

> “The special needs of patients who come from ethnic minorities require sensitive handling by the NHS.” (Merrison, 1979 7.61)

This was a sign of an *emerging* awareness of different BEM health needs. It was to result in qualitative and quantitative studies looking at access to healthcare by patients from these populations. As early as 1964, Patterson had drawn attention to the additional medical needs of children of Afro-Caribbean origin. In the early 1980s, there was recognition of the emergence of non-insulin dependent diabetes amongst Afro-Carribean communities in London (Nikolaides et al, 1981) and later in Wolverhampton (Odugbesan et al, 1989). In 1980, Terry, Condie and Settatree drew attention to the high rate of stillbirths and perinatal mortality amongst South Asian women compared to Afro-Caribbean and European mothers for the first time. In 1984, McFadyen et al reported that the children of South Asian patients, from both India and East Africa and born at Northwick Park Hospital, Harrow, were significantly lighter in weight than those with European parents.

Interest during the 1980s had started to focus on the South Asian community in the UK. During the 1960s South Asians had come to the UK to work in various industries, such as clothing in Leicester and brick making in Peterborough (Jaspal, 2015). In 1972, almost 60,000 South Asian citizens were expelled *en masse* from Uganda (Jamal, 1976). Together with people from Kenya, Tanzania and Malawi, it is estimated that from the early 1960s to the mid-1970s between 150,000 and 200,000 South Asians had settled in the UK (Anders, Burgess and Portes, 2018). About 20,000 people, who had been expelled from Uganda, settled in Leicester and so by 1981 the South Asian population of the city was almost 60,000 (Marrett, 1989). The city's South Asian community now comprises at least 37% of the population (Leicester Population, 2020) and most of the studies presented in this submission were based in Leicester. Indeed, by 2018 the South Asian ethnic groups made up the second largest percentage of the population throughout the UK (7.5%) (National Ethnicity Data, undated).

Studies across the United Kingdom began to examine the experience of patients from South Asian and other BEM communities who had diabetes, breast cancer and coronary artery disease. Comparisons were made with the experience of contemporaneous White patients and so management and care issues that had previously been overlooked were identified. Coronary artery disease drew particular interest from researchers, possibly because of its high morbidity and mortality

South Asian patients in Leicester, who were at greater risk of coronary artery disease than the White British population, were experiencing significant delays in diagnosis and receiving appropriate treatment, so resulting in poorer outcomes (Lear *et al* i and ii, 1994). Similar findings were also reported from Newham in London (Wilkinson *et al*, 1996). Unfortunately, the impact of the work by Lear et al (i and ii, 1994) was damaged by the retraction of a subsequent study from the same unit due to "deliberately entered false data into the study in order to produce a particular result." (Shaukat et al, 1997, Dyer, 2003) The overall impact of Shaukat et al's (1997) study on publications into discriminatory and disparate care was likely to have been unfavourable. However, the original observations by Lear et al (i and ii, 1994) remain valid. For example, delays in arrival at hospital and delays in interventions to manage myocardial infarction in South Asian patients continue to be an issue, as demonstrated in a recent study from Birmingham (Kendall *et al,* 2012). Indeed, there is a disparity in implantable cardioverter defibrillator therapy, which is significantly lower for South Asians than White British patients, in the United Kingdom (Mistry *et al,* 2020). Mistry *et al* (2020) were unable to determine whether this difference was due to "cultural acceptance or an unbalanced consideration". However, it is of interest that the National Institute for Health and Care Excellence (NICE) recently estimated that the cost of such a defibrillator and its maintenance, over a 15-year period, ranged between £28,000 and £34,000 (NICE, 2017).

Diabetes also emerged as a major problem in the South Asian community. In 2004, a study of 734 South Asian diabetic patients in Southall showed a markedly increased predisposition to cardiovascular disease compared with Europeans, especially in younger people (Mather, Chaturvedi and Fuller, 1998). However, there have been few studies which have examined the nature and quality of care received by South Asian patients with diabetes in the long-term. One such report from Nottingham showed South Asian patients with diabetes were less likely to have either their blood pressure or serum creatinine checked by general practitioners over the limited period of 1 year (Christopher and Kendrick, 2004).

Differences in the nature of the support and treatment offered to women from South Asian communities can also be seen in the management of breast cancer. In one study, Pakistani women were less likely to be offered radiotherapy or hormone treatment than White women (Jack, Davies and Møller, 2009). A systematic review of the poor uptake of breast and cervical cancer screening by South Asian women concluded that incorrect addresses, language and cultural barriers were significant factors (Sokal, 2010) and this continues to be the case (Woof et al, 2020). The National Cancer Patient Experience Survey (2018) reported Asian patients' rating of their overall experience of care was the lowest, followed by Black patients, compared to all other groups. There is a recurring tendency by researchers and policy makers to attribute such differences in cancer care to social and cultural factors (Chouhan and Nazroo, 2020 p. 91). However, such issues are not unique to cancer and a recent study on culturally competent care for South Asian patients with inflammatory bowel disease recognised that gastroenterology services failed to address barriers to utilising services (Mukherjee *et al*, 2020). For example, the simple provision of adequate translation services has been shown to have a significant benefit on patient experience, with better communication and more culturally relevant information (Ahmed *et al,* 2015).

The picture, which emerges from these studies, is of a diagnosis and treatment inequality for South Asian people across a range of chronic conditions. However, there had been no studies on whether this was true within gastroenterology and my research presented in this critical appraisal focused firstly on how and whether this was the case for gastrointestinal disease.

Gastrointestinal Disease:

Chronic gastrointestinal diseases requiring life-long therapy were increasingly recognised as major causes of significant morbidity from the 1970s onwards. The scourge of peptic ulcer disease was brought under control by the introduction of cimetidine. So, for young and middle-aged people, ulcerative colitis, Crohn's disease and coeliac disease are the main conditions within this group of chronic diseases. Achalasia is a progressive and debilitating disease of older people and, although uncommon, leads to multiple endoscopic and surgical interventions.

In parallel with the recognition that patients from BEM communities were experiencing sub-standard care, the traditional view that such chronic gastrointestinal diseases were uncommon in African and Asian BEM communities started to be questioned. This followed from studies in Birmingham (Benfield and Asquith, 1986) and Leicester (Jayanthi et al, 1992, Probert et al, 1992). This belief had been largely based on the anecdotal work of Dennis Burkitt, who attributed any alleged lower incidence in both migrant South Asian and African communities living in East Africa to their high unrefined fibre intakes. (Burkitt, 1973 and 1979) As a consequence of such thinking, most clinicians considered chronic gastrointestinal diseases uncommon in South Asians and interpreted the classical signs of these conditions as due to infective causes, acquired during visits to East Africa, India, Pakistan or Bangladesh (Bandaranayake, 1986). Little attention was, therefore, given to gastrointestinal disease in migrant populations in the UK.

By the early 1990s, Crohn’s disease and ulcerative colitis were first recognised to be common amongst South Asian migrants in both Leicester (Jayanthi *et al*, 1992 i, Probert *et al*, 1992 i) and Tower Hamlets (Jayanthi *et al*, 1992 ii and Probert *et al*, 1992 ii). During the same period, the highest incidence of coeliac disease in the world was reported amongst Punjabis in Leicester (Sher *et al*, 1993). A study of colorectal cancer in Leicestershire, from 1981 to 1991, showed younger patients had a trend towards increased frequency (Gee and Mayberry, 2000). This finding was confirmed in a later study with South Asian patients presenting at a younger age, but they also had more advanced disease (Norwood *et al*, 2009). Clearly, the burden of chronic gastrointestinal disease and colorectal cancer in the South Asian population in the UK was significant and studies had indicated that it was both increasing and affecting the younger generations.

With such significant changes, it was important to investigate whether there were any barriers of access to healthcare services or treatment, which could lead to poorer outcomes. The purpose of my research was firstly, to map out patterns of care for BEM communities, in particular the South Asian community. Subsequent to these studies, which demonstrated that there was widespread disparate care experienced by the South Asian community across a range of chronic gastrointestinal diseases over prolonged periods, my subsequent research considered responses from organisations tasked with ensuring equality within the NHS. This second focus of my research was on the role of structural racism in contributing to these disparities.

Institutional or Structural Racism and its consequences:

The events of the evening of 22 April 1993, when Stephen Lawrence, a Black teenager, was murdered, whilst waiting for a bus, in Eltham, London and the inadequate investigation by the Metropolitan Police, led to a public inquiry conducted by Sir William Macpherson. The report considered that police were institutionally racist. The concept was crystallised by Macpherson as:

> “The collective failure of an organisation to provide an appropriate and professional service to people because of their colour, culture, or ethnic origin. It can be seen or detected in processes, attitudes and behaviour which amount to discrimination through unwitting prejudice, ignorance, thoughtlessness and racist stereotyping which disadvantage minority ethnic people.” (Para. 6.34) (Macpherson, 1999)

Institutional or structural racism was recognised within the NHS shortly after publication of the Macpherson report (Collier, 1999). However, there has been little subsequent effective work done to limit its impact. Although discrimination against staff is frequently reported, that experienced by patients receives considerably less attention. Nevertheless, subsequent to

Macpherson (1999), the Public Sector Equality Duty (Equality Act (2010)) reflected changes in policy and formed the basis for the statement in the NHS Constitution that:

> "Legal duties require NHS England and each clinical commissioning group to have ***regard*** to the need to reduce inequalities in access to health services and the outcomes achieved for patients." (emphasis added) (Department of Health, 2015)

In 2013, NHS Monitor (*later renamed NHS Improvement!*) was tasked with issuing Provider Licences to Trusts and among the conditions is:

> "4 (b) reducing inequalities between persons with respect to their ability to access those services" (Monitor, 2013)

Organisations, such as Trusts, Clinical Commissioning Groups and NHS Improvement, need to act in ways which are consistent with their ethos and the NHS Constitution for England of 2021 states:

> "It has a wider social duty to promote equality through the services it provides and to pay particular attention to groups or sections of society where improvements in health and life expectancy are not keeping pace with the rest of the population."

However, in 2019 the *British Medical Journal* published an editorial on the health experiences of BEM patients and related it to "decades of evidence of disparities in health outcomes related to ethnicity" (Kmietowicz *et al*, 2019). It reported that:

> "The evidence is clear on the discrimination and prejudice against patients and staff from ethnic minorities. What is less clear is the

> appetite of health systems in the UK and around the world to tackle age-old health inequalities based on race and ethnicity."

Indeed, there have been no reports of responsible organisations ever taking action on the basis of ethnic or religious discrimination. As Salway *et al* (2016) have pointed out, this is often due to managers and teams not considering that tackling ethnic healthcare inequities is part-and-parcel of their job.

Current failures to take effective action have helped engender distrust in BEM communities, as reflected in poor uptake of the Covid-19 vaccination program (Robertson et al 2021). During the Covid-19 epidemic, Dr Raghib Ali, UK government advisor and epidemiologist, reinforced negative attitudes to structural racism within healthcare, when he said:

> "If structural racism was an important problem, not saying it doesn't exist, but if it was an important problem in healthcare outcomes, you'd expect it to be reflected not just in Covid but with other outcomes as well." (Editorial, 2020)

Similar views have been reiterated in the recent *Report* by the Commission on Race and Ethnic Disparities (2021), where the conclusion concerning health in BEM communities was:

> "These factors are complex but this is no way an overall negative picture for ethnic minority groups, and the Commission believes that more should be done to learn from those ethnic minorities that have better health outcomes despite being more deprived to improve health for all ethnic groups, including White ethnic groups." (p.213)

Limited attention was given to the poorer outcomes for many diseases experienced by BEM communities, as summarised in the comment:

> “racism and discrimination are not widespread in the health system, as is sometimes claimed” (p. 219)

and consistent with the Chairman’s view that one chapter should have been entitled:

> ‘The end of BAME (Black, Asian and minority ethnic)’ p. 9

Changes Needed to Address Structural Racism:

Understanding and effectively addressing how racism affects health is critical to improving population health and reducing ethnic inequities in health. The situation is even more pressing for elderly members of BEM communities (Burholt, Wenger and Shah, 2002). For example, the Race Disparity Audit (Cabinet Office, 2018 p.46) found Pakistani and Bangladeshi people over 65 years old had a particularly poor health-related quality of life. In order to achieve significant improvement, there will need to be policy changes directed at reforming institutional cultures, as well as tackling issues of social deprivation and racism (Chouhan and Nazroo, 2020).

As Williams, Lawrence and Davis (2019) have pointed out there is now a need to examine which structural processes are involved in the production and continuation of disparate care, including consideration of the role of immigration. This submission looks at the actors which control the patient experience in a systematic way from the clinical interface through to the regulatory bodies. Weaknesses in earlier studies included a failure to investigate differences in delivery of care over prolonged periods, confirmation of findings through checking the validity of data by using different methods of collection and using comparable approaches across different geographical areas. There were no investigations of management responses to disparate care or of potential legal solutions.

This critical appraisal assessed whether disparate care was an issue for patients with chronic gastrointestinal diseases. The initial study deals with the management of ulcerative colitis in a cohort of patients across a 10-year period. This leads on to a study of access to expensive biologic therapy for Crohn’s disease in the same Trust. Both studies demonstrated disparate care for South Asian patients. Access to biologic therapy was then assessed across a range of Trusts in England and the initial results confirmed. A subsequent study, about 5 years later, demonstrates that there has been no improvement and disparate care is also seen amongst other BEM communities. The situation with regards to a different chronic gastrointestinal disease, namely achalasia is examined. The incidence in South Asian people was determined for the first and only time. The reality of cancer risk in this condition is assessed by metanalysis. Then the forms of current treatment were examined across a range of trusts and South Asian patients are more likely to be exposed to new procedures, namely Per Oral Endoscopic Myotomy (POEM), as practitioners develop their skills. The attitudes of Trusts and other regulatory bodies are examined and the potential solutions considered in a detailed analysis of inquiries and judicial review. This critical appraisal also presents a collection of review papers which were written in conjunction with these studies.

2. Aims and description of the research programme:

The overriding question addressed by this research programme was:

> *"To determine the scale, nature and reasons for disparities of healthcare in England and Wales for South Asian minority patients with chronic gastrointestinal diseases, with some consideration of other BME communities."*

Its main objectives were:

1. To undertake systematic reviews of chronic gastrointestinal diseases in the South Asian communities in the United Kingdom and identify problematic areas in the delivery of healthcare and make comparison with the experience of other BEM communities
2. To assess whether chronic gastrointestinal diseases, such as achalasia, had a comparable incidence in the South Asian community compared to the White British community and whether cancer risk is a significant issue.
3. To establish whether there was evidence of disparate care to the South Asian community across England, using chronic gastrointestinal diseases as an exemplar and whether this was long term and/or related to high-cost therapies.
4. To identify the response of various governmental agencies to evidence of disparate care and available legal solutions.

In order to achieve these objectives, the research programme was divided into four stages, which were:

1. Reviews to establish the relative incidence of major gastrointestinal diseases in the South Asian population and, therefore, the need to consider whether they are receiving equal treatment:

The published reviews presented in this dissertation considered studies on the incidence of inflammatory bowel disease, coeliac disease, oral disease and colorectal cancer among South Asian patients. Within these reviews, issues related to access to diagnosis and therapy were investigated and the effectiveness of various solutions assessed. In addition, attitudes to national screening and surveillance programs for prevention and early detection of premalignant or early malignancy were separately reviewed and the reasons for disparate uptake considered. The issues identified in this latter review have direct relevance in day-to-day clinical management decisions.

2. Studies to determine the incidence of achalasia in the South Asian community, assess the long-term cancer risk of this condition and examine patterns of care.

Earlier studies conducted in Leicester defined the incidence of inflammatory bowel disease as higher in South Asians compared to the White community(Jayanthi et al. i, 1992; Probert et al. i, 1992.However, there were no data on the incidence of achalasia in the South Asian community in Leicester or, indeed, anywhere in the world. In addition, there had been no definitive study to determine cancer incidence in this condition. Its particular relevance to studies on disparate care lay in the fact that this is a condition which is commonest among the older sections of society. The review of issues concerned with delivery of care had determined that the elderly experience particular difficulties in this area (Mayberry and Farrukh, 2012).

3. Studies of the treatment of inflammatory bowel disease and disparity of care

These studies were organised so as to investigate firstly whether there was evidence of disparate care in the management South Asian patients with chronic gastrointestinal disorder, namely ulcerative colitis in Leicester and Leicestershire. The approach adopted was to follow a cohort of patients diagnosed with ulcerative colitis over a period of a decade and compare management decisions made during that time by review of their individual records. This was and is the only study to adopt such an approach.

The second study investigated the provision of expensive biologic therapy to patients with a different chronic gastrointestinal disorder, namely Crohn's disease in Leicester and Leicestershire. This study was based on an analysis of the records of all patients entered into the treatment register for this condition.

The third study investigated whether disparate care in the delivery of biologic therapy was widespread across Trusts which served substantial South Asian populations. It used a Freedom of Information (FOI) approach to obtain these data. As part of the study, data was collected from Leicester to allow direct comparison with that obtained by review of individual clinical records in the previous study. This allowed validation of data obtained by an FOI.

The fourth study again used an FOI approach to assess whether disparate care was seen amongst other BEM populations, namely Afro-Caribbean and Eastern European. Validation of the data obtained on this occasion was confirmed through inclusion of two trusts with significant South Asian populations, where disparate care was again seen.

4. Follow-up studies of response in NHS trusts:

A study of the responses by NHS trusts, Health and Well-being Boards and Clinical Commissioning Groups, where there was evidence of disparate care for patients with inflammatory bowel disease from the South Asian community was conducted one year after they were informed of the issue. In addition, similar questions were put to the Care Quality Commission, NHS Improvement and the Equality and Human Rights Commission, which are the bodies with statutory responsibility for ensuring equitable delivery of care. Responses were analysed using a themes analysis.

As a result of the lack of action by these bodies, a detailed review of the legal options available to BEM communities to deal with disparate care was undertaken. This included an assessment of the role of Royal Commissions, statutory and non-statutory inquiries and judicial review.

In the subsequent chapter, a critical review of the submitted papers is presented. The papers will be grouped together under three separate headings:

1. Original studies on the provision of care to minority communities with chronic inflammatory bowel disease.
2. Original studies in achalasia.
3. Studies of managerial responses and legal solutions.
4. Review.

This format was chosen to demonstrate linkages between studies.

3. An Analysis of Published Papers

Original studies on the provision of care to minority communities with chronic inflammatory bowel disease:

The following papers provide an original analysis of the care of minority communities in England with Crohn's disease and ulcerative colitis. The studies were conducted using different methods in different populations at different times and so through triangulation confirm that disparate care is widespread and significant.

They are largely presented in the chronological sequence in which the research programme developed, although due to variations in time to publication, this is not necessarily reflected in the date of the paper.

Farrukh, A. and Mayberry, J. (2016)
'Patients with ulcerative colitis from diverse populations: the Leicester Experience.'
Medico Legal Journal **84(1),** pp. 31 – 35

This original study was the first study to consider disparities in the delivery of care to patients with ulcerative colitis of South Asian origin over a 10-year period. It remains unique and demonstrated that South Asian patients were significantly less likely to see a consultant and more likely to be discharged. Although admitted to hospital more often, South Asian patients underwent fewer investigations and were less likely to be in a surveillance program for detection of colorectal cancer.

The strengths of this study include the requirement that all patients had been newly diagnosed, with histological evidence of ulcerative colitis, in order to be eligible for inclusion. This cohort of candidate patients was then reviewed to ensure that they had been resident within the defined catchment area around Leicester for the same decade and so had received treatment within the same NHS trust.

The clinical records of all candidate patients were reviewed by one of two researchers and a standard pro forma completed. A sample of records were checked for similarities in scoring. There was no significant discrepancy, but data for this correspondence across scorers was not included in the published report. It would have added to the strength of the results section, if this had been the case.

The siting of the study in Leicester also gave added strength as it is one of the few cities in England where there have been detailed earlier epidemiological studies of inflammatory bowel disease. In addition, the city has one of the largest South Asian communities in the UK, comprising almost half of its total population. So, there was a clear potential for a robust investigation of disparate care, because of significant numbers of patients with ulcerative colitis from both communities. Confirmation of the strength of this study comes from the similar mortality of this cohort to that in a previous study, conducted a decade earlier (Probert et al, 1993). This similarity gives further support to the accuracy of the findings of disparate day-to-day care.

The fact that the study was conducted a decade after the cohort of patients was identified, rather than from the beginning, gives added strength to the study. It shows what clinicians did in real life rather than if they knew they were under observation.

A limitation of the study was the fact that 109 of 372 candidate cases had been destroyed, were incomplete or could not be traced. However, as 76% of the 263 candidate cases were rejected as not meeting the criteria for inclusion in the study, it is possible that of the 109 lost files 26 cases may have been eligible. However, this assumption has underlying weaknesses as, in general, case notes of patients with active inflammatory bowel disease are seldom lost or destroyed, because of their need for on-going care.

As a consequence of this study, which had indicated South Asian patients with ulcerative colitis were less likely to receive detailed care, a separate study of access to expensive treatment was undertaken.

Farrukh, A. and Mayberry, J. (2015)
'Apparent discrimination in the provision of biologic therapy to patients with Crohn's Disease according to ethnicity.'
Public Health **129 (5),** pp. 460 - 464

This original study is again the first study to consider disparities in the delivery of care to patients of South Asian origin, but on this occasion, with Crohn's disease. It was based in Leicester and again required review of individual cases and their records.

Its purpose was to investigate whether disparate care was seen in a different condition to ulcerative colitis, although with similar clinical characteristics, and to specifically consider expensive treatment, in the form of biologic therapy. On this occasion, the study was conducted retrospectively and was based on a register of patients who have received either infliximab or adalimumab, over a four-year period. Of the 139 patients, who received such treatment, only 13 were South Asian. The expected number of South Asian patients ranged between 33 and 52, depending upon the approach adopted to make the estimate. The number of South Asian patients who received biologic therapy was significantly below any of the calculated expected number.

A major strength of this study is the centralised register for all patients with inflammatory bowel disease receiving this therapy. The register is kept scrupulously, because of the cost of the therapy. A further strength of the study is the detailed information available on the epidemiology of Crohn's disease in Leicester and of the population structure of the city. However, one limitation to the epidemiological data is that the measure for prevalence of the disease was from the 1990s and it seems probable that by 2010 this figure was an underestimate for both communities. The main limitation to the study was that it could not provide any data on patients who had been offered biologic therapy, but chose not to have it. From recent work on the uptake of vaccination against Covid 19 by the South Asian community, it is possible that there may have been a reluctance to accept biologic therapy. It is possible that this could have been a contributory factor to the clear disparity between the South Asian and White British communities, but this will be addressed in a subsequent study, where uptake by Eastern European migrants was investigated.

The question which arose from this study was whether disparate care for both ulcerative colitis and Crohn's disease was confined to the Leicester area or was seen elsewhere within England. The subsequent study addressed this question.

Farrukh A & Mayberry J (2015)
'Ethnic variations in the provision of biologic therapy for Crohn's Disease: A Freedom of Information Study.'
Medico-Legal Journal **83(2),** pp. 104 – 108

This study identified three NHS trusts which provided disparate care to their South Asian and white British patients with Crohn's disease. In

Pennine Acute Hospitals NHS Trust, covering Oldham and North Manchester, Barking, Havering & Redbridge University Hospitals NHS Trust and University Hospitals of Leicester NHS Trust significantly lower than expected numbers of South Asian patients received treatment with biologic therapy. This contrasted with six other trusts with significant ethnic minority communities where there was no evidence of disparate care.

This study used a different methodology to identify patients and a major strength was its confirmation of discriminatory care that had previously been demonstrated at University Hospitals of Leicester NHS Trust. The original study had used a register of patients, with review of their clinical records. This study utilised Freedom of Information requests and so was based on an analysis of computer records of clinic attendances held by each of the trusts. Although the number of cases in Leicester differed between the two studies, the proportion, who were from the South Asian community, was the same, giving confidence to the result that there is evidence of disparate care, as demonstrated by less ready access to biologic therapy.

The main weakness of the study is that there was no independent confirmation of the accuracy of the difference in treatment patterns at Pennine Acute Hospitals NHS trust or at Barking, Havering & Redbridge University Hospitals NHS Trust. The collection of data depended upon the approach taken by the hospital staff and there can be no certainty that similar techniques for searching the databases were used at the different trusts. However, this study was not a comparison between trusts but rather what happened within a trust.

This study demonstrated that discrimination in the provision of appropriate medical care to the South Asian community occurred outside of Leicestershire, but was not seen in every trust studied. The questions arising from these studies included whether such disparate care was seen in other minority communities and whether, with time and greater awareness, this became less. The next study investigated these issues.

Farrukh, A. and Mayberry, J.F. (2020)
'Apparent disparities in hospital admission and biologic use in the management of inflammatory bowel disease between 2014 – 2018 in some Black and Ethnic Minority (BEM) populations in England.'
Gastrointestinal Disorders **2(2),** pp. 141 – 151

This study used Freedom of Information methodology to investigate provision of biologic therapy in the management of inflammatory bowel disease in trusts with significant Afro-Caribbean and Eastern European communities. As a comparator, two trusts with significant South Asian communities, but which had not been previously studied, were also included.

In Bristol, Nottingham, Derby and Burton, Princess Alexandra Hospital Trust in Harlow, Essex and Kings College Hospital NHS Foundation Trust in South London, Afro-Caribbean patients were treated significantly less often than White British patients. Eastern European migrant workers, were admitted significantly less often in Croydon and the Princess Alexandra Hospital NHS Trust in Essex. In both North West Anglia and Princess Alexandra Hospital South Asian patients were significantly less likely to receive biologic therapy than White British patients. Clearly, Afro-Caribbean patients with inflammatory bowel disease experienced the same level of discrimination as seen in South Asian communities. The recent experience with Covid 19 vaccination raised the possibility that one explanation could be a reluctance to utilise modern therapeutic interventions. However, similar disparate care was seen in the management of people of Eastern European origin, who had inflammatory bowel disease.

There is no published evidence to suggest that Eastern European patients have a different view about biologic therapy than Western European patients; so lack of access to biologic therapy in minority communities seems widespread and to transcend cultural differences.

The strengths of this study include the consistent finding that University Hospitals of Birmingham NHS Trust showed no evidence of discrimination against Afro-Caribbean patients compared to White British patients, as it had not in the case of South Asian patients with Crohn's disease, as shown in the 2015 study. However, trusts with significant South Asian populations, such as in Peterborough and Harlow, had comparable findings to those reported earlier from Leicester, Havering and Redbridge and Acute Pennine Trust, covering Oldham and North Manchester, which had shown disparate care in the prescription of biologic therapy in the 2015 test.

The main weakness in this study concerned data on the population served by the trusts. In general, they were unable to provide an ethnic breakdown and reliance was placed on population data from the conurbation in which the trust was situated. However, the area served by a trust does not correspond with political boundaries, within which population data are collected. Data on the prevalence of inflammatory bowel disease in the Afro-Caribbean community is severely limited, with the only realistic estimates coming from Derby, and this means that, together with the population data issue, the expected number of cases may be inaccurate. Nevertheless, the magnitude of difference in provision of biologic therapy was extremely large in some trusts with statistical significance at a level of $p < 0.00001$.

This study was conducted later than previous studies and has shown no improvement in access to biologic therapy. In addition, there is clear evidence that patients from Afro-Caribbean and Eastern European communities are just as unlikely to receive appropriate treatment as is the case of South Asians. These studies have been concerned with chronic inflammatory bowel disease. The next step was to consider a different chronic gastrointestinal disease.

Ideally, such a disease would be of comparable incidence in white British and South Asian communities and would affect older sections of society, which are often poorly represented in cohorts of patients with inflammatory bowel disease. In addition, it was considered desirable that disease should also carry a significant cancer risk, as in the case of both Crohn's disease and ulcerative colitis. The disease selected was achalasia.

Original studies in achalasia:

Although there have been a considerable number of studies on the incidence and prevalence of achalasia in the UK, there were none of which specifically looked at its frequency in the South Asian community. Therefore, prior to investigating patterns of care in achalasia, it was first necessary to assess its incidence in the South Asian community and also to confirm the reality of any association with later development of cancer.

Farrukh, A., De Caestecker, J. and Mayberry, J.F. (2008)
'An epidemiological study of achalasia among the South Asian population of Leicester, 1986-2005.'
Dysphagia **23(2),** pp. 161- 4

This original study was the first study of the incidence of achalasia in the South Asian population, anywhere in the world. It remains the only such study in which case was distinguished from non-case through a review of original case records and investigation. The overall incidence was 0.89

cases/10^5/year, with a figure of 1.79 cases/10^5/year (95% confidence interval 0.7–3.7) in the last quinquennium of the study.

The strength of this study lies in its use of a clear definition of achalasia prior to a review of individual patient's clinical records. A cohort of candidate cases was identified from four separate sources, namely hospital activities analysis, endoscopy records, manometry records and pharmacy records related to prescription of botulinum toxin. A further strength was in restriction of the study to residents of the city of Leicester, for which detailed population analysis was available.

The main weakness of the study lies in the absence of a contemporaneous study of the incidence of achalasia in the White British population of the city. However, earlier studies at various times during the last 50 years have shown that the incidence of achalasia in the UK has been fairly stable at about 0.8/10^5/year.

The incidence of the disease climbs steeply after the age of 50, with a peak at 17/10^5/year in those aged 80 or older. Achalasia met the criteria that were desirable for a suitable candidate as the second chronic gastrointestinal disease to be investigated. The following study addresses the issue of cancer risk in achalasia.

Gillies, C.L., Farrukh, A., Abrams, K.R. and Mayberry, J.F. (2019)
'Risk of esophageal cancer in achalasia cardia: A meta-analysis.'
JGH Open **3(3),** pp196 – 200

This was the first meta-analysis of 16 studies drawn from a pool of 27 studies on the occurrence of oesophageal cancer in patients with achalasia identified over a period of 50 years. The analysis was stratified between cancers identified in the first year after diagnosis of achalasia and cancers identified in subsequent years. The incidence rate of oesophageal cancer in achalasia patients was estimated to be 1.36 (95% CI: 0.56, 2.51) per 1000 person years, which is over 10 times higher than the general population incidence rate.

The main strength of the study was its size in that it involved 4389 patients, identified from reports across the world, with 73 cases of oesophageal cancer. By stratifying the cancer risk the effect of an oesophageal cancer mimicking achalasia in its presentation was eliminated.

Weaknesses of the study included its 50-year time span, so involving studies when endoscopy was not commonly performed, resulting in possibly less frequent identification of cancer. It was also decided to include two studies from South America where Chagas disease can cause a megaoesophagus. However, of the 343 patients from Chile and Argentina only 17 tested positive for Chagas disease. Whether any of the 11 patients who developed oesophageal cancer had Chagas disease was not reported. The proportion of patients developing cancer in South America (3.2%) was significantly greater than elsewhere (1.5%) ($z = 2.32$, $p < 0.02$).

This study confirmed that achalasia is a significant risk factor for development of cancer in the affected organ, so strengthening the rational for its use as a comparator to inflammatory bowel disease. The subsequent paper investigated the pattern of management experienced by patients with achalasia from White British and South Asian communities.

Farrukh, A. and Mayberry, J.F. (2021)

***'Original observational study on disparate treatments for achalasia experienced by patients of white British and South Asian ethnicity**.'*

Annals of Esophagus doi: 10.21037/aoe-20-72: http://dx.doi.org/10.21037/aoe-20-72

This was the first study to consider whether there was disparate care related to ethnicity in the management of patients with achalasia. Patients were identified through Freedom of Information requests to 13 trusts with significant South Asian communities. South Asian patients received a different pattern of treatment to their White British counterparts and were significantly more likely to have a POEM procedure in inexperienced centres. The study also demonstrated that different patterns of treatment were not linked to levels of social deprivation.

The strength of this study is demonstrated by the close correspondence between the number of cases for Sandwell and Birmingham obtained through the freedom of information request and those in a study by different authors using a different method based on nationally coded data from Hospital Episode Statistics and The Health Improvement Network (Harvey et al 2019).

The main weakness in the study is that no sample of notes was checked for accuracy the diagnosis. However, Freedom of Information requests only generate anonymized data and so from conception, such a check could not be incorporated into the search protocol. It is of note that despite data being anonymized, six of the 13 trusts declined to provide specific figures on the fallacious basis that this would allow identification of patients. When a further analysis, using the ranges provided by these six trusts, was performed the differences in the types of care provided were still significant.

This study has demonstrated that patients from ethnic minorities in the UK with a different chronic gastrointestinal disease experience different care to their white British counterparts and this includes greater exposure to new treatments in the hands of inexperienced clinicians.

Arising out of these studies is the question of what has been the attitude of responsible bodies, such as NHS trusts, clinical commissioning groups and other national organisations, such as the Care Quality commission and the Equality and Human Rights Commission. This question is addressed in the following study.

Studies of managerial responses and legal solutions:

Farrukh, A. and Mayberry, J.F. (2019)
'Does the failure to provide equitable access to treatment lead to action by NHS organisations? The case of biologics for South Asians with inflammatory bowel disease.'
Denning Law Journal **31,** pp. 77 – 91

This is the first and only study to collect data on the response to disparate care by organisations responsible for ensuring equality of healthcare delivery. It is based around the three trusts identified in the initial multicentre study of biologic therapy in Crohn's disease. Neither NHS trusts, Clinical Commissioning Groups nor Health and Welfare Boards took any action in response to their discriminatory practice in the year subsequent to the study by Farrukh and Mayberry (2015 ii). The Care Quality Commission and NHS Improvement denied statutory responsibility for such issues and the Equality and Human Rights Commission had never investigated any cases of such discrimination nationwide.

The strength of this study is based on its use of data provided by the trusts themselves. In addition to the responses by the trusts, confirmation was obtained from local and national monitoring bodies that no action had been taken with regards to discrimination in the delivery of care. Responses were provided from departments within the organisations, which were responsible for public liaison.

The study could have been improved by direct discussions with Equality and Diversity officers within the responsible trusts, but such assessments are unlikely to have been allowed in the context of the official responses.

At a local level, there is little prospect of trusts which exhibit disparate care changing their stance and so the question arises as to what legal remedies are open to BEM communities. These possibilities are considered in the following study.

Farrukh, A. (2020)
'What are the legal mechanisms for seeking solutions to disparities in the delivery of care in the NHS and where does liability lie?'
Denning Law Journal **32,** pp. 51 - 86

This comprehensive review considered the potential role and effectiveness of Royal Commissions, statutory and non-statutory enquiries and judicial review as possible methods for dealing with the issue of disparate care to BEM communities. Its conclusion was that, at present, the only solution lay with individual actions for substandard care, resulting in poorer outcomes, through the tort of negligence.

The strength of this study lay in the wide-ranging review of the role of commissions and enquiries, specifically related to the NHS and consideration of the scope of judicial review. Its weakness lies in the fact that, as to date, none of these bodies have considered disparate care for ethnic minorities.

Reviews:

Throughout the duration of the original studies on disparate care, published work on the experience of people of South Asian origin, in utilising healthcare services in the UK, was collected and this resulted in a series of reviews related to the original research and wider issues. The review papers emerged from background studies to the research program and do not relate directly to its chronological order.

Mayberry, J.F. and Farrukh, A. (2012)
'Gastroenterology and the provision of care to Panjabi patients in the UK.'
Frontline Gastroenterology **3(3),** pp. 191 – 198

Farrukh, A., Sayeed, S. and Mayberry, J.F. (2014)
'Oral health and the provision of care to Panjabi patients in the UK.'
Dental Update **41(7),** pp. 629 – 636

Farrukh, A. and Mayberry, J.F. (2019)
***'Inflammatory bowel disease and the South Asian diaspora**.'*
JGH Open **3(5),** pp. 358 – 360

Farrukh, A. and Mayberry, J.F. (2019)
'Evidences of differences and discrimination in the delivery of care: colorectal screening in healthy people and in the care and surveillance of patients with inflammatory bowel disease.'
Gastrointestinal Disorders **1(2),** pp. 253 – 260

These reviews summarise the known epidemiology of various gastrointestinal diseases in the South Asian communities in the UK. They also drew attention to issues experienced with use of services and accessing appropriate translators and provision of information in appropriate languages. The main weaknesses identified through these reviews are the failure to address issues of discrimination, delivery of care according to ethnicity and to attribute these failures to some inbuilt deficiency in the communities.

4. Discussion:

Three chronic gastrointestinal diseases, namely ulcerative colitis, Crohn's disease and achalasia, were chosen as exemplars of conditions which require long-term clinical management involving both primary and secondary care sectors. Achalasia acted as a useful contrast in that it predominantly affects older people and effective treatment requires surgical-type interventions rather than ongoing medical treatment.

The main findings in the nine studies presented in this dissertation were:

a. Patients with chronic ulcerative colitis from South Asian minority communities in Leicester were seen significantly less often by consultants, underwent fewer investigations and were discharged significantly more than White British patients over a decade.
b. South Asian patients with Crohn's disease are less likely to have equitable access to expensive treatments, namely biologic therapies, in Leicester and other NHS trusts in England. Patients with chronic inflammatory bowel disease from Afro-Caribbean and Eastern European minority communities also experience poorer access to expensive biologic therapies.
c. Chronic gastrointestinal disease, in the form of achalasia, is, at least, as common in the older South Asian community as in White British people. In all communities there is a significant increased risk of oesophageal cancer in the years following diagnosis.
d. South Asian patients with achalasia are more likely to be offered a new form of treatment, whilst practitioners are developing their skill, than White British patients.
e. NHS organisations and national bodies charged with ensuring equitable access to care fail to take effective actions to remedy deficiencies.

f. Effective legal mechanisms by which minority communities can seek redress are limited and, currently, individual action based on the tort of negligence is the only route open to patients who have experienced poorer care.

The studies presented have systematically considered standard treatments provided over a period of a decade as well as access to expensive treatments. In addition, they examined the nature of treatments offered to patients and identified, for the first time, the fact that elderly South Asian patients were disproportionately represented on the learning curve of endoscopists offering a new treatment, namely POEM. The studies have demonstrated evidence of widespread, persistent and disparate care in the management of BEM patients with chronic disease.

Data in these studies were drawn from a variety of sources. These included pathology, endoscopy and radiology records, as well as a patient register. In the studies using these techniques, the diagnosis and patients' ethnicity could be confirmed directly. In other studies, particularly those based on Freedom of Information data, the accuracy of the diagnosis, treatment provided and patient ethnicity depended upon coding by hospital clerical staff and, subsequently, on Freedom of Information Officers applying the correct search terms to Trust's databases, such as Hospital Episode Statistics. Inaccurate coding by clerical staff and lack of motivation or interest on the part of Information Officers are recognised sources of significant potential errors.

Although such data are collected to better inform NHS and government policy, data provided under Freedom of Information requests were anonymised, so preventing any sampling to check on their accuracy. These data counted episodes and may not have directly correlated with individual cases. However, they did measure differences within Trusts, as in the Leicester studies, where the proportion of patients receiving different biologic treatments and the male to female ratio were the same, whether assessed by individual cases or by episodes. This comparison lends support to the reality of the disparate care. In the Freedom of Information studies of inflammatory bowel disease, comparisons were not made across Trusts, but only within Trusts. In this way, the effect of differences in coding practice or motivation of officers in different trusts was eliminated.

Data on ethnicity were sourced from relevant local government departments. There are limitations to such data, which include: Trust and Local Authority boundaries not being co-terminous, ethnicity being self-defined and migrant transient working populations varying with time. However, there are no other independent sources to confirm these government generated data.

In direct observational studies, based on known patients, variability in the quality of the data collected was minimised by a second observer checking sample data collection sheets. However, in Freedom of Information studies, an error in coding could be further amplified by poor search questioning of the data base by the officer. The restriction of comparisons within individual trusts ensured that such errors were constant across the ethnic groups within that trust. It is perhaps one of the most striking aspects of these studies that, even with such limitations on the data, the differences in care experienced by various BEM communities are so large.

The unique nature of this collection of papers is their bringing together evidence of widespread disparate care within one medical discipline covering prolonged periods, different geographical areas and different diseases. It has also demonstrated institutional inertia, indeed, indifference to clear evidence of disparate care, with no organisation prepared to take responsibility, despite statutory requirements that they should.

The research presented in this dissertation is a unique and make a substantial contribution to a much wider discussion about access to health care by South Asian communities in the United Kingdom. It aligns with previous isolated studies, which have shown evidence of disparate care for certain aspects of various diseases, in a range of communities. The studies presented here demonstrate widespread disparate care for several chronic gastrointestinal conditions across England over prolonged periods, indicating the depth and seriousness of the issue.

My studies reinforce findings from reports of treatments for coronary artery disease in Leicester (Lear *et al* i and ii, 1994), Newham (Wilkinson *et al*, 1996) and Birmingham (Kendall *et al*, 2012), which demonstrated poorer care for South Asian patients. This included limited access to expensive treatment in cardiology (Mistry *et al,* 2020). However, such studies were usually isolated and snapshots in time. The longest ongoing study was in diabetes and covered a period of only one year. (Kendrick and David, 2004). The only study which considered the disparate types of treatments received by different communities was in breast cancer management, where Pakistani women were less likely to be offered radiotherapy or hormone treatment than White women (Jack, Davies and Møller, 2009).

The findings in this dissertation have shown that there are clear differences in the pathways of access to care for chronic gastrointestinal diseases for minority groups compared to the White British population. However, Black and Ethnic Minority (BEM) populations have long been blamed as the cause of their own ill-health (Donovan, 1986). For example, following a meeting of the Royal Society of Medicine in 1964, Patterson suggested that issues of poor child health in migrant communities was down to parental ignorance and that this could be remedied through appropriate and continuous education. In her paper, she wrote:

> “I would like to emphasize that the medical services have specific tasks in ensuring that no coloured children are deprived of medical care through ignorance, that their basic needs are met by continuous

> health education and that those who work with coloured immigrants should be trained to understand their problems and to communicate with them."

These findings bring to mind comparable issues which were identified by the MacPherson Inquiry, which labelled such attitudes as "institutional racism". In recent times, there has been a tendency to dilute the impact of this term through use of an alternative, namely "structural racism". Structural, or institutional, racism encompasses social forces, institutions, ideologies, and processes which interact and create and reinforce inequalities (Powell 2008).

Structural racism can be expressed in subtle ways. In the USA, for example, Hall et al (2015) have shown that most healthcare providers have a positive bias in favour of White patients and there is also evidence that physicians, who treat a disproportionate share of Black patients, have less training and less access to important clinical resources (Bach et al, 2004). In the UK, language discord between patients and their general practitioners has been shown to cause less satisfaction with communication (Brodie et al, 2016). Research on the nature of barriers, which limit access by BEM patients to healthcare, tends to attribute roles to language issues (Barron et al, 2010), lack of health literacy, (Rowlands et al, 2015), cultural problems (Alexaxis et al, 2015) and an inability to engage with the services provided (McFadden et al, 2018). In 2008, the Department of Health had recognised that a complex matrix of issues played a significant part in preventing effective communication between BEM patients and their general practitioners. These included:

- Dysfunctional communication between health care organisations and patients.
- Lack of choice and voice.
- Community understanding of the healthcare system.

- Inflexibility in the system.
- Continuity of care and the patient-doctor relationship.
- Poor NHS links with local communities. (Lakhani, 2008)

However, many managers and teams do not consider tackling ethnic healthcare inequities as part-and-parcel of their job (Salway et al, 2016). Indeed in 2021, the Commission on Race and Ethnic Disparities stated:

> “The Commission’s view is that individuals and communities of all ethnicities should be encouraged to take control of their own health. This would be both in relation to changing their own behaviours and in taking part in research studies to see what is effective.” (p. 228)

There is a recent tendency to adopt the stance referred to by John Calmore, when he said: "Social injustices are now seen as natural misfortunes" (Marshall, 2004). Such natural misfortunes may be linked to education, income, diet and housing; whilst failing to recognise the role racism has played.

Viewed within the context of racism, the findings of the studies summarised in this report raise questions as to why BEM patients should travel down different health care pathways to the White British community and to the role played by healthcare professionals in those decisions. Most disturbingly, there is a clear lack of appetite to address these issues, with open denial of their existence by trusts, which had provided the data (Farrukh and Mayberry, 2019 i). These concerns are heightened by the fact that those institutions, with statutory obligations to ensure equitable delivery of care, seem unaware of this role and have never taken any relevant action to implement change (Farrukh and Mayberry, 2019 i). This research does not provide an explanation for this institutional inertia. It is open to speculation as to whether a challenge through judicial review might be the necessary stimulus to encourage bodies, such as the Care Quality

Commission, NHS Improvement or the Equality and Human Rights Commission, to fulfil their statutory duties (Farrukh 2020).

Issues of disparate care should be important to NHS trusts and other related organisations. This body of research makes it abundantly clear that little or no improvement has been seen in these areas, despite the CLEAR Action Plan of:

> “**C**ommission equitably for a diverse population
>
> **L**eadership: ramp up the profile of the issues in local health economies and identify leaders who will make it happen
>
> **E**ngage, enable and empower citizens through literacy and shared decision-making. Be on the side of’ patients and agree rights and responsibilities
>
> **A**dvance the quality of care through practice accreditation and robust GP appraisal
>
> **R**ecord ethnicity data and monitor progress towards equality and quality of care.” (Lakhani, 2008)

This program emerged out of a review commissioned by the then Secretary of State for Health, Alan Johnson, as to why BEM communities found it more difficult to access general practice services than white patients. Despite being an official document of the Department of Health, the response on page 2 states:

> “Action required N/A” (*N/A = Not Applicable*)

and its purpose was:

> “For information”

The integration of issues of equality of care into the NHS Constitution and the provision of Provider Licences to trusts by NHS Improvement has not translated into action on disparate care. To overcome institutional inertia there needs to be a local initiative and significant work by committed individuals within that trust, as demonstrated by the work of Cowan and Woodger (2006) in South London. However, there has not been long-term follow-up to assess whether the beneficial impact of small working groups on institutional racism is maintained. It does, however, lend support to the concept that institutions are made up of individuals and it is those individuals that formulate its policies in practice. Indeed, the long-term study on care of patients with ulcerative colitis in Leicester raised “the possibility that some senior doctors discriminated against South Asian patients and chose never to see them.” (Farrukh & Mayberry, 2016). Further support for such a proposition comes from the fact that there were a limited number of Trusts where there was no evidence of disparate care (Farrukh and Mayberry 2015 ii).

The other aspect which this research has shown is the failure of current statutes and statutory instruments to have any impact on trusts and related organisations, which fail to meet their legal obligation to ensure equitable delivery of care (Farrukh and Mayberry, 2019 i). There is no effective monitoring and no penalties have been imposed on these organisations for these failures. Managers are not being held accountable for these deficiencies in their services. At present, judicial review and legal actions based on the tort of negligence provide the only possible remedy for disadvantaged patients and patient groups. To date, neither approach has been utilised in connection with disparate delivery of care (Farrukh, 2020). Clearly, there is a need for an easily accessible and open legal framework through which patients from minority communities can raise such issues without facing the significant expense associated with judicial review. In practice, this is likely to require recognition of earlier failures, new legislation and restructuring of organisations with clear definitions of their tasks, with appropriate external monitoring.

This research has exposed how little is known about why people with chronic gastrointestinal disease make decisions about their treatment and, more particularly, the role of cultural factors in those decisions. One significant component is the nature of barriers in access to care and linked with this is the role of practitioners in guiding patients down a particular healthcare pathway. The complexity behind such decisions can be seen in a theoretical study of the choices made by patients with Crohn's disease, in relation to the ability of a surgeon (Harris and Mayberry, 2014). It is only through a better knowledge of such issues that remedial action can be taken, so as to improve the overall care of BEM patients with chronic diseases. Applicable techniques will need to include qualitative interviews and observations amongst both practitioners, patients and family members. A different approach would be to adopt Latour and Woolgar's (1979) technique of investigating the daily activity of working scientists, as in *Laboratory Life.* This could be applied to hospital doctors and so help clarify how decisions are reached. Through such an insight it may be possible to develop relevant and effective programs for change.

5. Conclusion:

The studies presented demonstrate clear evidence of disparate care received by patients from ethnic minorities, including access to expensive therapies, greater exposure to new interventional techniques on the early part of operators’ learning curve, and for periods of up to 10 years in established care programs. These differences in standards of care are seen across three different chronic gastrointestinal diseases, namely ulcerative colitis, Crohn’s disease and achalasia. They are widespread across trusts, which serve minority communities, and affect South Asians, and as recently demonstrated, Afro-Caribbeans and Eastern Europeans as well (Farrukh and Mayberry, 2020). Despite the fact that statutes and statutory instruments require equality of care to be monitored, those national organisations charged with this responsibility have failed to institute any action related to patient ethnicity. Indeed, NHS trusts and local organisations, tasked with equitable delivery of healthcare deny the findings based on data, which they have supplied. National organisations, such as the Care Quality Commission and NHS Improvement, do not recognise their statutory obligations and have conducted no studies to address these inequalities. Even the Equality and Human Rights Commission has taken no action on these issues and appears to have no active research programme related to equality of care within the NHS and hospital services, in particular. Against such a background, the only form of potential legal remedy, for a community, is through judicial review and, for an individual, through legal action in the tort of negligence.

This research has raised a number of questions, which need to be addressed in future research, including:

1. What are the causes for disparate care across a wide range of ethnicities?

2. Why are government bodies reluctant to accept the evidence derived from their own data?
3. What are the roles of various actors in this pattern of discriminatory care? The actors are: patients, doctors and managers.
4. What legal remedies could be developed to address these inequalities and how could they be made sufficiently robust to overcome current institutional inertia in dealing with these issues?
5. The best hope for addressing the inequalities in health that have been demonstrated in this research is through a new statutory requirement for the regular reporting of differences in management and outcomes by ethnicity for a range of named diseases. Trusts and Clinical Commissioning Groups then would be required to provide such data annually. Its mode of collection and validity would be assessed by an independent commissioner, such as the Parliamentary and Health Service Ombudsman, who would publish the results of their findings. The executive board and management of failing organisations would be held legally responsible for any inaction.

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7. Publications:

Due to issues with page size in various publications and clarity of print, it has not always been possible to follow the PhD submission guidelines for page outlay.

Original Article

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Patients with ulcerative colitis from diverse populations: The Leicester experience

Affifa Farrukh and John Mayberry

Abstract

Background: Ulcerative colitis is common in migrant communities. There is evidence that access to care in general is impaired among such communities. The purpose of this study was to investigate whether South Asians experienced the same quality of care as English patients with ulcerative colitis.

Method: The study assessed clinical care in the decade subsequent to diagnosis through a retrospective review of case notes. Newly diagnosed patients who lived in Leicester were identified and the frequency and type of consultation, in-patient admissions, surveillance colonoscopies, discharge rates, surgery and death were recorded.

Results: Of 372 candidate cases identified, 70 met the criteria to be included in the study. Forty-two were of English origin and 28 South Asian. South Asian patients were significantly less likely to see a consultant and more likely to be discharged. South Asian patients were admitted to hospital more often but had significantly fewer tests than European patients. This trend was also seen in surveillance colonoscopy, although it did not reach significance. Despite these differences in the provision of care, surgical and death rates were comparable.

Conclusions: Patients with ulcerative colitis who are of South Asian origin receive poorer quality clinical care than their European counterparts.

Keywords

Ulcerative colitis, quality, ethnicity, discrimination

Introduction

In a country with a nationalised and free health-care service, it would be hoped that access for patients with gastrointestinal disorders should be independent of social deprivation, ethnicity, gender or religious affiliation. Unfortunately, work on access to colorectal cancer screening has shown that discrepancies in the delivery of care do exist.[1] For example, the uptake of colonoscopy was 20% lower among Asians with a positive faecal occult blood test (FOBT) result. Even when other factors, such as deprivation, were taken into account, the colonoscopy uptake rate for the whole Asian group was half that of non-Asians. Particular groups such as the Hindu-Gujeratis and Muslims had colonoscopy uptakes one-third of the non-Asian population.[1] There has been considerable speculation on the reasons for such differences including the role of social deprivation[2] communication barriers[3] and religious discrimination.[4] On a practical front, a recent study of 30 registered nurses in Leeds showed that they had limited understanding of the local Pakistani community. There was evidence of poor preparation to meet the needs of an ethnically diverse society and the presence of racism emerged among the explanations for the deficits between participants' expectations and the reality experienced in care settings.[5] Although ethnic minorities are sometimes viewed as not accessing particular health services because of religiously based explanations for illness or disability, Bywaters et al. demonstrated that "institutional and structural racism" also lies behind lack of access to appropriate services,

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compounded by the fear of being misunderstood by “out-group professionals”, in other words those from a different ethnic or religious background.[6]

The fact that ulcerative colitis was common amongst the South Asian community was recognised in the early 1990s.[7] Within the UK, there was already an established tradition of guidelines sponsored by the British Society of Gastroenterology, which provided standards by which to compare treatment across communities. At this time, there was evidence within Leicestershire that patients from the South Asian community with coronary artery disease did not receive comparable care to their European counterparts.[8] However, the withdrawal of a separate study has raised difficulties for those investigating discrimination in the delivery of care.[9,10] Nevertheless, problems with dissemination of health-care information would appear to be widespread with significant differences in knowledge between different language groups in Leicestershire.[11] The impact of such differences has been the subject of considerable speculation.[12–14]

Method

Selection of cases

The purpose of the study was to review the experience of patients with ulcerative colitis during the decade subsequent to their diagnosis in Leicester. Potential cases were identified through a trawl of histology records for samples taken between 1996 and 1998. This analysis of pathology records identified both new and follow-up patients who had either flares of their disease or were in a surveillance program. In order to separate case from non-case the clinical records were then retrieved. From these candidate cases, patients were selected in whom the diagnosis was first made during the three years between 1 January 1996 and 31 December 1998. In order for a patient to be included within the study the following criteria needed to be met:

1. Symptoms consistent with inflammatory bowel disease.
2. Histology supportive of a diagnosis of ulcerative colitis.
3. More than one episode of disease activity during the decade subsequent to the initial biopsy.
4. Continued residence within the catchment area for University Hospitals of Leicester NHS Trust during the decade of study.

If the initial diagnosis was Crohn’s disease or when there was a change in diagnosis during the subsequent decade, such cases were excluded from the study. If candidates were not resident in Leicester or Leicestershire throughout the decade of subsequent management, they were also excluded from the study.

Data collection

Records from all three hospitals in the catchment area were reviewed together with notes from community hospitals where appropriate. The following data were collected from the patients’ clinical records and entered into a pro-forma:

1. Name.
2. Date of birth.
3. Gender.
4. Ethnicity.
5. Number of consultations with senior doctors.
6. Episodes of in-patient treatment.
7. Whether the patient had had screening offered and the type of screening they had undergone, namely flexible sigmoidoscopy or colonoscopy.
8. Other substantial procedures such as radiology.
9. Whether they had undergone surgery for ulcerative colitis.
10. If the patient had been discharged from hospital follow-up.
11. If the patient had died during the decade following diagnosis.

Data analysis

Data were compared between English and South Asian patients. Within each ethnic group a comparison was made between men and women. Appropriate statistics were used including unpaired t tests and z tests to compare rates and proportions. The software employed was StatsDirect.

Results

The histology records identified 372 patients in whom biopsies were suggestive of inflammatory bowel disease between 1 January 1996 and 31 December 1998. Of these, 263 clinical records were retrieved and analysed. One hundred and nine records had been destroyed, could not be traced or were incomplete. One hundred and ninety-three of the 263 candidate cases, in which the notes had been retrieved, were rejected as they failed to meet the diagnostic criteria. Reasons included an initial diagnosis before 1 January 1996, Crohn’s disease rather than ulcerative colitis or a subsequent failure to establish any form of inflammatory bowel disease.

Of the 70 cases in which a diagnosis of ulcerative colitis was established, 42 were of English origin and

28 were South Asian. In both ethnic groups male patients were commoner than female patients (Table 1). However, English patients were on average 10 years older than their South Asian counterparts. ($t = 2.6$, $p < 0.01$)

Various aspects of patient care were assessed. English patients were significantly more likely to be reviewed by a consultant than was the case for South Asians. ($z = 1.66$, $p < 0.048$, Table 2). However, when South Asian patients did see a consultant, the frequency of those consultations was comparable between the two ethnic groups. This would suggest that there were consultants who did not see patients from the South Asian community who attended their clinics but rather they were seen by junior members of the teams. During the decade after diagnosis, 61% of South Asian patients required in-patient care for their ulcerative colitis, compared with 45% of European patients. Significant investigations were undertaken in 79% of South Asian patients compared to 67% of English patients. However, when English patients needed investigations, they had significantly more investigations covering a wider range of modalities than did South Asian patients ($t = 2.1$ $p < 0.02$, Table 2). In addition, overall a South Asian patient with ulcerative colitis was 2.6 times more likely to be discharged from hospital follow-up than a European patient ($z = -2.3$, $p < 0.01$, Table 2).

Between 7 and 10 years after diagnosis, national guidelines, at that time, required that patients should be offered a screening colonoscopy to define the extent of disease and potentially identify dysplasia.[15] In this cohort of patients, 43% of Europeans were offered a screening colonoscopy compared to 32% of South Asians ($z = 0.9$, ns) (Table 2).

During the three-year period between 1 January 1996 and 31 December 1998, there were 10 consultant gastroenterologists working in the area, all of whom were of European origin. Of the 4 consultants appointed in the 10 subsequent years only 1 was of South Asian origin. All were male.

In summary, South Asian patients were significantly less likely to see a consultant and more likely to be

Table 1. Demography of newly diagnosed patients with ulcerative colitis.

	European		South Asian	
	Male	Female	Male	Female
Number	22	20	16	12
Age at diagnosis (±standard deviation)	48.4 (±14)	43.1 (±21)	37.3 (±13)	33.3 (±16)
Interquartile range	40–59	24–62	27–48	21–44

Table 2. Aspects of clinical management of newly diagnosed patients with ulcerative colitis over the subsequent decade in Leicester.

	European			South Asian			z statistic	p
	All	Male	Female	All	Male	Female		
Number		22	20		16	12		
Screening		11	7		6	3		ns
i. Flexible sigmoidoscopy		2	0		0	0		ns
ii. Colonoscopy		9	7		6	3		ns
Patients reviewed by a consultant during the decade		15	10		5	4	1.66	<0.048
Frequency of consultant review	2.2			2.1				ns
In-patient care								
Number admitted		7	12		10	7		ns
Frequency of admissions for these patients		1.6	2.1		1.9	2.3		ns
Substantial procedures								
Number who had undergone such procedures		14	14		12	10		ns
Frequency of such procedures amongst these patients		3	2.9		2.4	2.6		ns
Overall frequency of investigations	2.9			2			t = 2.1	<0.02
Discharged from hospital care		7	4		8	11	−2.3	<0.01

ns: not siginificant.

Table 3. Outcomes amongst newly diagnosed patients with ulcerative colitis in Leicester over the subsequent decade of management.

	European		South Asian	
	Male	Female	Male	Female
Number	22	20	16	12
Surgery	2	5	2	1
Deaths	2	1	1	0

discharged. South Asian patients were admitted to hospital more often but when serious investigations were required they had significantly fewer tests than European patients. This trend was also seen in access to surveillance colonoscopy, although it did not reach significance. Despite these differences in the provision of care, surgical and death rates were comparable (Table 3).

Discussion

This review suggests that patients with ulcerative colitis who are of South Asian origin receive poorer quality clinical care than their European counterparts. However, it is limited by the fact that the study was retrospective and 29% of the candidate case records had been destroyed, were incomplete or could not be retrieved. If the proportion of cases to non-cases was comparable in both the retrieved and non-reviewed notes then our review potentially missed 29 cases. Despite these limitations, there are areas of particular concern which include management by more junior members of the clinical team, more frequent hospital admission, fewer investigations, more infrequent surveillance and more frequent discharge from hospital follow-up. The fact that fewer South Asian patients were seen by consultants but when they were seen by consultants the frequency of seeing a senior doctor was similar raises the possibility that some senior doctors discriminated against South Asian patients and chose never to see them. This issue is separate from the overall poorer care offered to patients from an ethnic minority. Clinical outcomes such as surgery and mortality are objective and easy to measure but do not reflect the nuances of day-to-day management. During recent years, the emergence of standards of care in inflammatory bowel disease will mean that more objective assessments than "significant investigations" and frequency of "review by consultant" can be made.[16] However, the indications from this study are that we need to critically review our approach to patients from ethnic minorities and ensure that they have equitable long-term access to appropriate health care including senior review, hospital-based management and colonoscopic surveillance. There is also a place to consider why there appears to be no significant difference in surgical and mortality rates. Larger studies might identify differences. It may also be that differences would emerge over longer periods such as 20 or 30 years and, of course, inflammatory bowel disease is a chronic life-long condition. An alternative view is that the impact of "good quality" clinical care may actually have no impact on the course of the disease and may simply provide patients and clinicians with the illusion that regular intervention is of value. Of course, measures linked to surgery and mortality do not deal with the impact of the condition on education, employment, fertility and family life or the development of associated diseases such as arthritis and osteoporosis. For many patients it is the support linked to these issues that is important.

Work in the UK on mass screening of healthy people has shown that although intentions were comparable across various cultural groups, attendance for flexible sigmoidoscopy was considerably lower among Asians (54%) compared with White (69%) or Black (80%) respondents. The UK colorectal cancer screening pilot reported an overall uptake of 62% for FOBT for English people, but uptake was poor in the South Asian community, with figures for Muslims as low as 32%. The highest figure amongst South Asians was for Hindus, but was still only 44%.[1] In a subsequent analysis of the national colorectal cancer screening program in the UK, the most ethnically diverse areas had the lowest uptake (38%) compared to other communities where the figure was between 52 and 58%. These differences were independent of social, economic and personal status.[17,18] These data lend support to the apparent differences in the delivery of care identified in this study. Further support comes from the experience of ostomists during the 1990s when an understanding of issues related to siting the stoma and the sari line were expressed together with difficulties in accessing specialist advice.[19]

This study would suggest that we need to radically review the way in which we deliver care to patients with inflammatory bowel disease from minority communities. Quality of care is defined in terms of client-centred services, meeting needs and expectations. It is an ongoing process that incorporates clients' rights and their satisfaction with the system. It helps patients make well-judged decisions based upon information, understanding and options, i.e. informed choice rather than coercion or exclusion. Indeed, the Stephen Lawrence Enquiry concluded:

> It is incumbent upon every institution to examine their policies and the outcomes of their policies and practices

> to guard against disadvantaging any section of our communities.[20]

In the case of patients with inflammatory bowel disease, this will only be achieved through active involvement of patients from minority groups in shaping the clinical services we provide. Such advisory groups may be difficult to form and will need support and encouragement. Perhaps, this will be most evident when we see the nature of our service changing in response to their suggestions because as yet they are not demands.

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Original Research

Apparent discrimination in the provision of biologic therapy to patients with Crohn's disease according to ethnicity

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ABSTRACT

Objectives: The objective of the study was to investigate whether patients from a South Asian ethnic background who had Crohn's disease received equivalent access to therapy with biologics compared to patients with an English background.

Study design: The study was retrospective and covered the period 2008 to 2012. It was based on a register of all patients with Crohn's disease in Leicestershire who are treated with biologics. The prevalence of Crohn's disease in Leicestershire amongst South Asian and English patients was known from earlier studies and from these data it was possible to make corrections to allow for the difference in frequency of the condition between the two communities.

Methods: All adult patients who received biologics for treatment of Crohn's disease in Leicestershire between 2008 and 2012 were reviewed and their gender and ethnicity noted as well as whether they had received infliximab or adalumimab. The expected numbers of patients who should have received these therapies were calculated in two ways:

i. The proportion of the total population of cases based on prevalence data (the preferred method);
ii. The proportion who should have received the treatment based on the population distribution within Leicester and Leicestershire.

Results: One hundred and twenty six patients with Crohn's disease who received treatment with biologics were European and 13 South Asian. The patients' gender was also noted and 67 European patients (53%) were female as were six Asians (46%). Based on prevalence data, the expected distribution of the treatment would have been for 97 of the patients to have been European and 42 to have been South Asian. If 126 European patients warranted treatment, on this basis the expected number of South Asian patients in need of biologic therapy would have been 55. Based on the smaller predicted number of South Asian patients (42) the difference is significant at $P < 0.0001$ [Proportion difference = 0.69 (95% confidence interval = 0.539278–0.809576]. For the difference to be extinguished the number of English patients who should have received biologic therapy would have been as low as between 30 and 39 cases (based on the calculated proportion of 97 and the actual figure of

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126 European patients respectively). Based on a population composition, rather than prevalence data, in which 24% of the Leicester community should have been of South Asian origin, 33 patients would have received biologics compared with 92 patients of English origin (66%). This is significantly different to the 13 patients who did receive treatment ($z = -3.2$, $P < 0.001$).

Conclusions: Suggested reasons for these differences have included concerns about the animal origins of infliximab as well as difficulties associated with accessing the service, such as the provision of information in an appropriate language through appropriate media. For those who come from groups with significant social deprivation there is often a readiness to accept more limited clinical services. However, such differences themselves, are examples of discrimination in clinical practice.

Introduction

The introduction of biological therapy for Crohn's disease has revolutionised the clinical management of this condition. Its role was recognised by all gastroenterologists, although ease of access to this form of treatment may have varied from region to region within the UK. The development of Technical Appraisals by NICE on the use of adalimumab and infliximab has ensured that the rationale behind use of these treatments is clear and evidence based. Against such a background it would be hoped that discrepancies in treatment would be abolished and that access would be independent of social deprivation, ethnicity, gender or religious affiliation. Unfortunately work on access to colorectal cancer screening has shown that discrepancies in the delivery of care exist.[1] Uptake of colonoscopy was significantly lower among Asians with a positive FOB test result (54.9% vs 74.4% for non-Asians). Even when other factors such as deprivation were taken into account, the colonoscopy uptake rate for the whole Asian group was half that of non-Asians. Particular groups such as the Hindu-Gujeratis and Muslims had colonoscopy uptakes one third of the non-Asian population.[1] There has been considerable speculation on the reasons for such differences including the role of social deprivation,[2] communication barriers[3] and religious discrimination.[4] A review of the care received by South Asian patients with ulcerative colitis in the decade subsequent to their diagnosis showed that they were seen less often by senior clinicians, underwent fewer surveillance endoscopies and were discharged from follow-up more frequently.[5] Against this background of discrepancies in care in the UK, an audit of treatment with biologics for Crohn's disease was undertaken. Another of the driving factors was the fact that in both Atlanta[6] and Baltimore[7] studies have shown that African Americans are between two and three times less likely to receive biologic therapy than white patients. Similarly Hispanics in Miami were less likely to receive this form of treatment[8]

Method

Data for the period 2008 to 2012 were collected from a central register for these patients with Crohn's Disease. This register does not record details of patients for whom biologic therapy was considered inappropriate. Data collected included ethnicity and gender together with details on whether treatment was with infliximab or adalumimab. In order to make some comparison with other specialties, enquiries were also made as to whether comparable registers for the use of biologics in conditions such as rheumatoid arthritis and psoriasis existed in Leicestershire and they did not. In addition there are no data on the prevalence of these conditions locally or nationally or by ethnicity in the UK. The absence of such data would also have prevented an assessment of the likely numbers of patients from different communities with rheumatological or dermatological conditions who should have received biologic therapy.

Data on the prevalence of inflammatory bowel disease, as opposed to its incidence, in the UK is limited. In the 1970s figures of $56/10^5$ were reported from Newport in South Wales.[9] During the 1990s the standardised prevalence of Crohn's disease in Europeans in Leicester was $75.8/10^5$ and among South Asians $33.2/10^5$.[10] By the mid-2000s the point prevalence in Tayside, Scotland was as high as $157/10^5$.[11] However, the Scottish data did not include a breakdown by ethnicity.

Using these data from Leicester the expected number of patients of South Asian origin was calculated as a proportion of the total cohort. In the 1990s the proportion of patients from the South Asian community was 0.3. A second calculation was made based on the population distribution within Leicestershire, with conservative estimates placing the South Asian population at 24% compared to 66% for the English community, with 10% of other ethnicities. Statistical comparisons of the actual and expected frequencies were compared using Stats Direct software.

Results

Between 2008 and 2012, 139 patients with Crohn's disease received biologic therapy in Leicester. One hundred and twenty six were European and 13 South Asian. The patients' gender was also noted and 67 European patients (53%) were female as were six Asians (46%).

The expected numbers of patients from either a South Asian or English background were calculated from work done on the prevalence of Crohn's disease in these communities in Leicester in the 1990s.[10] The expected prevalence in the South Asian community at that time was $33/10^5$ population and that in the English community was $76/10^5$ Recent work from elsewhere would suggest a higher prevalence in both communities and also that the disease may be reaching comparable levels of frequency.

Based on the prevalence of Crohn's disease in the community the expected distribution of the treatment would have been for 97 of the patients to have been European and 42 to have been South Asian. If 126 European patients warranted treatment, on this basis the expected number of South Asian patients in need of biologic therapy would have been 55. Based on the smaller predicted number of South Asian patients (42) the difference is significant at $P < 0.0001$ [Proportion difference = 0.69 (95% confidence interval = 0.539278–0.809576)]. For the difference to be extinguished the number of English patients who should have received biologic therapy would have been as low as between 30 and 39 cases (based on the calculated proportion of 97 and the actual figure of 126 European patients respectively).

Based on a population composition in which 24% of the Leicester community should have been of South Asian origin 33 patients would have received biologics compared with 92 patients of English origin (66%). This is significantly different to the 13 patients who did receive treatment ($z = -3.2$, $P < 0.001$).

The proportion of patients receiving infliximab therapy in the European cohort was 0.37 and in the South Asian group 0.46. These proportions are not significantly different [Proportion difference = −0.096 (95% confidence interval = −0.360 to 0.152)]. The proportion of patients who were male in the European cohort was 0.47 and 0.54 in the South Asian group. Again this difference was not significant [Proportion difference = −0.07 (95% confidence interval = −0.32 to 0.195)]. The gender distribution and choice of treatment within the two cohorts was similar and indicates that the groups were homogenous (See Table 1).

Discussion

There is a significant difference in the use of biologics for the treatment of Crohn's disease between the European and South Asian communities in Leicester. It is likely that similar differences exist in other cities throughout the UK and a study based on Freedom of Information requests lends support to this observation.[12] Unfortunately, there are no on-going registers of all patients within defined communities within the UK in whom a diagnosis of Crohn's disease or ulcerative colitis has been made. Most studies of incidence have been based on retrospective identification of cases. This means that the population potentially eligible to receive biologic therapy for Crohn's disease is unknown and rather comparisons have to be made looking at registers of patients who have actually received treatment. Although this limitation is a serious one it is not a reason to dismiss the magnitude of difference reported in this study in which 126 English patients received treatment compared to 13 patients or in Oldham and North Manchester where 1041 White British received treatment compared to ten South Asians between 2010 and 2012.

Table 1 – The provision of biologic therapy in Leicester between 2008 & 2012.

	European		South Asian	
	Male	Female	Male	Female
Adalumimab	41	39	5	2
Infliximab	18	28	2	4
Actual	59	67	7	6
Expected	59	67	26	29

Data were collected from a register of all patients receiving biologic therapy for Crohn's disease in Leicestershire.

Suggested reasons for these differences have included concerns about the animal origins of infliximab as well as difficulties associated with accessing the service, such as the provision of information in an appropriate language through appropriate media. For those who come from a group with significant social deprivation there is often a readiness to accept more limited clinical services.[3,13] However, such differences themselves, are examples of discrimination in clinical practice. Another suggestion as to the reasons for this difference is that South Asians have milder disease than English patients.

Biologic therapy is reserved in the UK for patients with severe active or fistulising Crohn's disease.[14] The mortality rate for patients of South Asian origin is directly comparable to that of English patients,[15] although a recent study from North West London has found that patients of South Asian origin have less penetrating disease than English patients and had surgery less often, although the reasons for this are not clear.[16] However, there is evidence that inflammatory bowel disease can affect the second generation of migrants from South Asia more severely than their parents.[17] It seems likely, therefore, that English and South Asian patients are broadly comparable in their experience of inflammatory bowel disease.

The UK would not be unique. In a study of three hospitals in Atlanta USA white patients were significantly more likely to receive multiple doses of infliximab (34% vs 11%, $P = 0.005$).[6] Similarly in a study of 406 patients from Baltimore, African Americans were less likely to receive infliximab (10% vs 20%; $P = 0.03$), or either 6-MP/AZA or IFX (28% vs 44%; $P = 0.005$).[7] In Miami the ratio for Hispanics was 22% compared with 56%.[8] It is known that in the north of England Panjabi patients with inflammatory bowel disease often come from groups with a poorer quality of life and tend to accept limited clinical services and this may be a factor for findings reported in this study.[13] Indeed in a study of 2161 patients who received biologic therapy for Crohn's disease in nine areas of the United Kingdom and who had been identified through a Series of Freedom of Information requests only 159 were of South Asian origin compared to the expected 213. Of particular note was the nine fold difference experienced in Oldham and North Manchester.[12]

Health disparities among racial and ethnic groups are influenced by the structural (socially or state-sanctioned), institutional and interpersonal aspects of a society and its health care systems.[18,4,19] Indeed, a study of 30 registered nurses in Leeds showed that they had limited understanding of the Pakistani community. There was evidence of poor preparation to meet the needs of an ethnically diverse society and the presence of racism emerged as explanations for the deficits between participants' expectations and the reality in care settings.[20] It should not, therefore, be surprising that there are significant differences in the care experienced by South Asian patients and European patients in the UK. Such differences are currently being reported in mental health,[21] diabetes and coronary artery disease,[22] colorectal cancer screening,[1] oesophageal and gastric cancer[23] as well as hip and knee replacement.[24]

Ethnic minorities are sometimes viewed as not accessing particular health services because of religiously based explanations for illness or disability. However, Bywaters and colleagues demonstrated that 'institutional and structural racism' also lies behind lack of access to appropriate services, compounded by the fear of being misunderstood by 'out-group professionals'.[18] Other explanations include the nature of medications, such as animal sources. However, in the case of biologics there is no evidence in favour of such an explanation with both communities making equivalent use of adalumimab. The concept of 'institutional racism' emerged from the Stephen Lawrence Enquiry which concluded:

> *It is incumbent upon every institution to examine their policies and the outcomes of their policies and practices to guard against disadvantaging any section of our communities.*[26]

This philosophy has been adopted across the public sector in the UK. For example, the NHS Constitution, in consistency with the Equality Act 2010, states:

> *You have the right not to be unlawfully discriminated against in the provision of NHS services including on grounds of gender, race, disability, age, sexual orientation, religion, belief, gender reassignment, pregnancy and maternity or marital or civil partnership status.*[27]

In its publication on Human Rights in Healthcare the Department of Health has gone further and advocated that:

> *NHS organisations .... have a positive obligation to take proactive steps to protect people from human rights abuses even if the harm is caused by private individuals rather than directly by the authority.*[28]

However, ethnic minorities still experience institutional racism within the NHS with evidence of a range of disparities in the delivery of health care across many specialties. Clearly this is also true for patients with Crohn's disease. McKenzie[25] has suggested that this concept of institutional racism provides a mechanism for dealing with these discrepancies in health care delivery that allows to:

(1) Focus on the actions of institutions rather than individuals;
(2) Target the results of practice rather than the intent;
(3) Acknowledge other forms of social stratification and their effects. For instance, gender, social class, or sexual orientation may interact with racial group to increase disparities;
(4) Identify the problem as ideological. Health disparities are brought about and perpetuated not only by culture, class, and sociopolitical forces external to medicine but also by the ideology of the medical profession. This ideology leads to ineffective or no action in the face of disparities.

It is now critical to develop programs to correct discrepancies in the delivery of care to ethnic and other minorities. They will need to be developed in conjunction with those communities so that barriers which limit access to care are effectively overcome rather than to hope that solutions can be imposed from outside. Essential to such an approach is the acceptance that such disparities exist rather than to have an ideology that fails to acknowledge the problem.

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Ethical approval

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Competing interests

None declared.

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Ethnic variations in the provision of biologic therapy for Crohn's disease: a Freedom of Information study

Affifa Farrukh and John F Mayberry

Abstract

In this study, we investigate whether the provision of biologic therapy for Crohn's disease is equitable across South Asian and English groups in NHS Trusts, which serve areas with significant ethnic variation. Data were requested from 10 NHS Trusts using a Freedom of Information (FOI) approach. Details of numbers of patients by ethnicity treated with infliximab or adalumimab for Crohn's disease between 2010 and 2012 were requested. Using population-based estimates of disease prevalence and Census data on population structure, observed and expected numbers who should have received treatment were calculated. In three Trusts, the number of South Asian patients who received such treatment was significantly less than British/White patients. These were: Pennine Acute Hospitals NHS Trust covering Oldham and North Manchester, Barking, Havering & Redbridge University Hospitals NHS Trust and University Hospitals of Leicester NHS Trust. The study is limited by several factors:

1. The only data available on prevalence in both English and South Asian communities comes from Leicester and was published in 1993. More recent data suggests that the prevalence of Crohn's disease now approaches $150/10^5$ compared to the $76/10^5$ for English patients which was recorded in Leicester. However, the two subsequent studies on prevalence which were published in 2000 from the North of England and 2010 from Scotland do not provide a breakdown by ethnicity.
2. The data were collected by administrative staff using a variety of approaches to their Trust's data bases and so the techniques used in each Trust are not comparable. In addition, studies from elsewhere suggest that the quality of FOI data is affected by the motivation of staff who collect the data.
3. With the exception of Leicester, there was no quality check on the accuracy of the data. In Leicester, 139 patients were on a register of biologic therapy and this compared with 343 patients reported by the FOI request. However, the proportions of patients by type of treatment and by ethnicity were comparable in the two data sets. This suggests that the data on ethnic differences reported by the FOI study reflects real differences.

Clearly, there are South Asian communities where patients with Crohn's disease appear not to receive appropriate treatment in the form of biologics, and the reasons behind this need further consideration and investigation. We need to develop robust methods of monitoring the provision of biologic therapy across ethnic groups and communities. It is unacceptable for there to be a difference based on such grounds.

Keywords

Biologics, ethnicity, Crohn's Disease, discrimination

Introduction

Recent work has demonstrated that the care received by South Asian patients with ulcerative colitis in the decade following diagnosis is not comparable to that of English patients in the same NHS Trust.[1] They were seen less often by senior clinicians, underwent fewer surveillance endoscopies and were discharged from follow-up more frequently. A separate study looked at the provision of biologic therapy for patients with Crohn's disease in the same NHS Trust and found that South Asian patients were between two and five times less likely to receive biologic therapy.[2] Such differences have been reported

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elsewhere. In both Atlanta[3] and Baltimore,[4] African Americans are between two and three times less likely to receive biologic therapy than white patients. Similarly Hispanics in Miami were less likely to receive this form of treatment.[5] The reasons are not clear but are unlikely to reflect religious beliefs or dietary practices. Work in other areas has shown that Punjabi patients from socially deprived backgrounds will often accept lower standards of care. Such health disparities among ethnic groups are influenced by institutional and interpersonal aspects of a society and its health care systems.[6,7] Indeed, a study of 30 registered nurses in Leeds showed that they had limited understanding of the Pakistani community. There was evidence of poor preparation to meet the needs of an ethnically diverse society and the presence of racism emerged as explanations for the deficits between participants' expectations and reality.[8] Against this background, a Freedom of Information (FOI) study was conducted to investigate whether the disparities identified in earlier studies were seen across a range of Trusts servicing areas with significant South Asian populations. This approach was chosen as such anonymised data should be openly available to the public and form part of the data which Trusts collect on care and ethnicity. Its main limitation is the fact that the data cannot be corroborated through reference to patient notes.

Method

Data on the ethnic composition of the area were obtained from local government statistics which were, in turn, based on the Experimental Population Estimates by Ethnic Group for local authority districts and higher administrative areas for England and Wales for 2009.[9] Overall South Asians made up 5.1% of the population in the United Kingdom. Based on Census data, those areas with a population in excess of 20,000 South Asians were identified (Table 1). With the exception of the Birmingham conurbation, this meant that in most of the selected areas South Asians made up 15% of the community or more. In total, 10 areas were identified in England which had a significant South Asian population.

A letter was sent to the FOI Officer at each of these Trusts. Each Trust was asked to provide information for the 3 years between 1 January 2010 and 31 December 2012. This included the number of patients treated for Crohn's disease in those hospitals which serviced areas with significant South Asian populations, as well as separate information for infliximab and adalumimab. For each drug, the Trust was asked to identify how many patients were:

A. British
H. Indian
J. Pakistani
K. Bangladeshi
Z. Ethnicity not stated

Table 1. Trusts approached with a Freedom of Information request to provide data on patients with Crohn's disease treated with biologics between 2010 and 2012.

- West Middlesex NHS Trust
- Heart of England NHS Trust
- University Hospital of Birmingham NHS Trust
- Pennine Acute Hospitals NHS Trust
- Heatherwood & Wexham Park Hospitals NHS Foundation Trust
- East Lancashire Hospitals NHS Trust
- Luton & Dunstable University Hospital NHS Foundation Trust
- University Hospitals of Leicester NHS Trust
- Barking, Havering and Redbridge University Hospitals NHS Trust
- Bradford Teaching Hospitals NHS Foundation Trust

This coding was based on the scheme proposed by the *Ethnic Code Category* of the NHS.[10] This was adopted on 1 April 2001 and overlapped with the Ethnic Category Code, which had been used prior to that date. In order to secure a comprehensive response, Trusts were also asked to provide data for this period using this earlier coding, if relevant. For this code data were requested for:

0. White
4. Indian
5. Pakistani
6. Bangladeshi

The data were analysed using the information on British/White coded patients as a baseline. From these data, expected numbers of South Asian patients (Pakistani, Indian and Bangladeshi) were calculated on the assumption that the prevalence in these communities was $33/10^5$ compared to $76/10^5$ in the English population.[11] These prevalence figures from Leicester are the only ones available for Crohn's disease in the United Kingdom which deal with frequency by ethnicity. There have been two subsequent studies from Middlesbrough[12] and Tayside,[13] which give overall values of about $150/10^5$. However, they do not provide an ethnic breakdown. The observed proportion of South Asians who received biologics was compared with the expected proportion, based on the Leicester ratio, using a z statistic (Stats Direct).

Results

Of the 10 areas with a significant South Asian population, 9 provided data. The tenth, Bradford, reported that it did not collect data on ethnicity. 2002 British/White patients were treated with biologics between 2010 and 2012 compared to 159 South Asian patients (Table 2). In three of the Trusts, the number of South Asian patients who received such treatment was significantly less than British/White patients. These were:

- Pennine Acute Hospitals NHS Trust covering Oldham and North Manchester
- Barking, Havering & Redbridge University Hospitals NHS Trust
- University Hospitals of Leicester NHS Trust

With the exception of the Heart of England NHS Trust, which covers Solihull, the remaining Trusts provided treatment with biologics comparable to the number that might be expected to receive treatment based on the prevalence ratio of 0.43 derived from epidemiological studies in Leicester in the 1990s. In the case of Solihull, significantly more South Asian patients received such treatment than would be expected.

In the University Hospitals of Leicester NHS Trust, an independent clinical register of patients treated between 2008 and 2012[2] was compared with the response from the Freedom of Information Officer between 2010 and 2012. The register identified a total of 139 patients treated over a 5-year period compared to 353 treated over a 3-year period reported by the FOI request (Table 3). There are no clear explanations as to why an FOI request should report a 2.5-fold greater rate of treating patients with biologics. However, there is internal consistency within the data in that there are

Table 2. Treatment with biologics for Crohn's disease between 2010 and 2012 by ethnicity as identified by a Freedom of Information request.

Area	White British (% population)	South Asian (% population)	White British who received biologics (no.)	South Asians who received biologics (no.)	South Asians expected to receive biologics (no.)
Hounslow & Richmond (West Middlesex NHS Trust)	68	21	36	8 or less	5
Solihull (Heart of England NHS Trust)	86	6.6	252	64	9*
Edgbaston and Selly Oak (University Hospital of Birmingham NHS Trust	83	6.5	12	4	1
Oldham & North Manchester (Pennine Acute Hospitals NHS Trust)	83	17	1041	10	97**
Slough (Heatherwood & Wrexham Park Hospitals NHS Foundation Trust)	68	32	49	10	4
Burnley (East Lancashire Hospitals NHS Trust)	88	12	118	13	7
Luton & Dunstable University Hospital NHS Foundation Trust	69	31	61	4	8
Barking, Havering & Redbridge University Hospitals NHS Trust	62	28	128	6	25***
University Hospitals of Leicester NHS Trust	60	26	305	40	57****

*$p < 0.0001$, $z = 6.04$, **$p < 0.0001$, $z = -8.2$, ****$p < 0.001$, $z = -3.6$, ****$p < 0.05$, $z = 1.88$.
The data from Pennine Acute Hospitals NHS Trust relate to "high cost drug treatment". The number of Asian patients expected to receive biologic therapy was calculated using the ration of 1 White English to 0.44 South Asian which is based on prevalence data from Leicester.

Table 3. A comparison of treatment in Leicester based on a review of the biologic register and data provided under a Freedom of Information search between 2010 and 2012.

	Adalumimab		Infliximab	
	White British	South Asian	White British	South Asian
Biologic Register	80	7	46	6
Freedom of Information Search	184	29	121	19

There were no statistical differences in the proportions of patients receiving biologics or in the types of biologics between the register and the Freedom of Information request.

no significant differences between the two sources of data and the ratio of adalumimab/infliximab treatment or in the ethnic composition of the treatment groups.

Discussion

There is significant variation between areas as to provision of biologic therapy by ethnicity. Although the robust nature of the data provided by an FOI request may be questioned, the findings are consistent with a report based on the clinical register for biologic therapy kept in Leicester.[2] Clearly, there would appear to be South Asian communities where patients with Crohn's disease do not receive appropriate treatment in the form of biologics. FOI data has significant limitations as demonstrated in this study. In general, there is no external corroboration of its accuracy. The method of collecting the data can vary between centres and may be affected by the motivation of those people who collect it. In this study, there was a significant difference in the number of patients identified through the FOI study compared to an independent register of cases. The reasons behind this apparent discrepancy need further consideration and investigation.

Suggested reasons for these differences in provision of biologic therapy between ethnic groups have included concerns about the animal origins of infliximab, as well as difficulties associated with accessing the service, such as the provision of information in an appropriate language through appropriate media. For those who come from a group with significant social deprivation, such as Punjabis in the north of England, there is often a readiness to accept more limited clinical services.[14–16] However, such differences, themselves, are examples of discrimination in clinical practice. The UK is not unique. In a study of three hospitals in Atlanta, USA, white patients were significantly more likely to receive multiple doses of infliximab (34% versus 11%, $p = 0.005$).[3] Similarly in a study of 406 patients from Baltimore, African Americans were less likely to receive infliximab (10% versus 20%; $p = 0.03$), or either 6-MP/AZA or IFX (28% versus 44%; $p = 0.005$).[4] In Miami, the ratio for Hispanics was 22% compared with 56% for White Americans.[5] In studies from the United Kingdom, there was evidence of poor preparation to meet the needs of an ethnically diverse society and racism emerged as one of the explanations for deficits in care.[8]

This study is based on data provided under FOI legislation. In the United Kingdom, FOI Act was enacted in 2000, and came into full force in 2005.[17] Shortly afterwards Meredith[18] wrote:

> "At its best, freedom of information should be a marker for openness and accountability in public services".

In a study of 16 papers, Fowler *et al.* investigated its use by medical researchers. It was clear that there was no way of assessing the quality of data collected.[19] They showed that although there is a legal requirement to disclose accurate information, the methodology for data collection may not be uniform and as a result there can be unknown biases within the data set. For example, work by Bourke *et al.*[20,21] has shown that officers are more inclined to be helpful if they know applicants and they are cordial. In our study, a standard letter of application was used and there were no personal approaches to FOI Officers. However, in line with other research using this methodology the way in which data were identified and collected varied significantly between Trusts. This is well illustrated by the fact that Bradford was unable to identify any method for identification of patients treated. These limitations contrast strongly with the situation in the United States where a similar act passed in 1966 led to a vast output in public health research.[22]

Conclusion

In conclusion, we need to develop robust methods of monitoring the provision of biologic therapy across ethnic groups and communities. It is unacceptable for there to be a difference based on such grounds and indeed it contravenes both the NHS Constitution and the Equality Act 2010.[17] In its publication on Human Rights in Healthcare, the Department of Health has gone further and advocated that:

> "NHS organisations ... have a positive obligation to take proactive steps to protect people from human rights abuses even if the harm is caused by private individuals rather than directly by the authority."[18]

Any system of monitoring needs to consider all patients put forward for biologic therapy and pay particular attention to those for whom such treatment is rejected. However, it must also ensure that patients from minority communities are informed about such treatments in a culturally appropriate way.

Two other limitations which affected the robustness of the data relate to the prevalence of Crohn's disease in ethnic groups and the accuracy of population data, especially as it related to the hospitals which provided biologic therapy. There has only been one study of the prevalence of Crohn's disease in ethnic groups in the United Kingdom.[11] It is now 20 years old and the overall prevalence of the condition has doubled in that time.[12,13] However, there is no reason to believe that the proportions of patients from various ethnic groups has changed. The second limitation is that Census population data relates to political geographical boundaries and these may not precisely correspond with hospital catchment areas. Despite these limitations, the difference in provision of biologic therapy in some areas is so profound that it cannot be explained away on the basis of weaknesses in the method of data collection or of uncertainties with regard to population size.

Conclusion

From this study, there is convincing evidence that there are some South Asian communities in the United Kingdom where patients with Crohn's disease appear not to receive appropriate treatment in the form of biologics. Despite limitations on the nature of the data, these differences are so profound that they clearly must reflect a real difference in the nature and quality of care received by South Asian patients with Crohn's disease in the United Kingdom. The reasons behind this need further consideration and investigation. We must develop robust methods of monitoring the provision of biologic therapy across ethnic groups and communities and so ensure that there is no suggestion of discrimination in the delivery of care.

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gastrointestinal disorders

MDPI

Communication

Apparent Disparities in Hospital Admission and Biologic Use in the Management of Inflammatory Bowel Disease between 2014–2018 in Some Black and Ethnic Minority (BEM) Populations in England

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Abstract: Discrimination in delivery of care to patients with inflammatory bowel disease has been reported in the UK with regards to the South Asian population. This paper explores whether it is also true for Afro-Caribbean and Eastern European migrant workers. Treatment was investigated in NHS trusts, which served substantial migrant and minority communities, through Freedom of Information requests for data on use of biologics or hospital admissions over a five year period. In Bristol, Nottingham, Derby and Burton, Princess Alexandra Hospital Trust in Harlow, Essex and Kings College Hospital NHS Foundation Trust in South London Afro-Caribbean patients were treated significantly less often than White British patients. Eastern European migrant workers, were admitted significantly less often in Croydon, and the Princess Alexandra Hospital NHS Trust in Essex. However, there was no evidence of barriers to access for these communities in Wye Valley Trust, University Hospitals of Bristol NHS Foundation Trust or Queen Elizabeth Hospital Kings Lynn. In North West Anglia both South Asian and Eastern European patients were significantly less likely to be admitted to hospital than members of the White British community. It is incumbent on all gastroenterologists to consider their own clinical practice and encourage their hospital units to adopt effective policies which remove discriminatory barriers to good quality care.

Keywords: inflammatory bowel disease; ethnicity; UK; discrimination; biologics; admissions

1. Introduction

Discrimination in the delivery of care and clinical management of patients with inflammatory bowel disease has been reported in the USA, Canada and the UK [1–6]. African Americans and Hispanics in the USA [1,4–6], and South Asian patients in the UK, received biologic therapy less frequently than white patients [2,3], and in the case of South Asian patients were seen less often by senior clinicians and more frequently discharged from hospital care.[7] In a national study of emergency admissions for ulcerative colitis and outcomes, King et al. (2019) found that Asian patients had a significant delay to surgery [8]. It was as long ago as 1988 that Bhopal first recognized the existence of racism and discrimination in clinical practice within the National Health Service (NHS) [9]. In 1998 South Asian cardiac patients in Leicester were shown to receive poorer acute care than their white counterparts. [10] During the 21st century Black and Pakistani women have received poorer care in the NHS than White women with breast cancer [11] and ethnic minority patients with renal disease are less likely to receive a donor organ [12]. This issue of discrimination is seen across the clinical spectrum in the NHS with patients from Black and ethnic minority communities receiving less labor-intensive therapies for treatment of psychotic disorders. [13] The reasons for such differences are uncertain, but clearly demonstrate that some ethnic groups experience barriers in access to good quality care and that this is also true for the management of inflammatory bowel disease in the South Asian community in England. The purpose of the current study was to investigate how widespread such issues are for patients with inflammatory bowel disease from other migrant and minority groups in England. The hypothesis was that patients with inflammatory bowel disease should have similar hospital admission rates and biologic therapy rates regardless of ethnic origin. The study was directed at NHS Trusts which served communities with substantial Black (Afro-Caribbean) and White Other (Eastern European) communities. Most of the selected Trusts served areas where such communities exceeded 10% of the population.

2. Methods

Freedom of Information requests were sent to ten Trusts. When data on the provision of biologic therapy was unavailable, the Trusts were asked to provide data on frequency of hospital admission. In all cases, Trusts were asked to provide data on the White British community. Other communities investigated were European, Afro-Caribbean and South Asian. The European communities investigated were of Irish origin or described as White Other. In those trusts, which were selected, White Other, largely referred to Eastern European transient workers, who largely came from countries such as Poland, Romania, Latvia, Estonia, Lithuania and Bulgaria. Within the European Union such citizens have the right of free movement and provide labor in agricultural and construction industries. Selected NHS trusts were asked to provide information on the number of patients with inflammatory bowel disease treated yearly with biologics between 2014 and 2018 through Freedom of Information (FOI) requests. The information requested was to be broken down into the following ethnic groups:

1. White British
2. White Irish
3. White other
4. Afro-Caribbean (often provided separately as African or Caribbean)
5. Bangladeshi
6. Indian
7. Pakistani

When these data were unavailable, hospital admissions for inflammatory bowel disease between 2014 and 2018 were requested by the same ethnic groups.

The NHS trusts which were approached were selected on the basis of having significant migrant populations, either as transient workers or permanent residents. The trust chosen were:

Croydon Health Services NHS Trust
Kings College Hospital NHS Foundation Trust
NorthWest Anglia NHS Foundation Trust
Nottingham University Hospitals NHS Trust
Queen Elizabeth Hospital King's Lynn NHS Foundation Trust
The Princess Alexandra Hospital NHS Trust
University Hospitals of Birmingham NHS Foundation Trust
University Hospitals of Bristol NHS Foundation Trust
University Hospitals of Derby and Burton NHS Foundation Trust
Wye Valley NHS Trust

All Trusts had a Department of Gastroenterology and provided specialist care for patients with inflammatory bowel disease and five contained a medical college. Population data by ethnicity was obtained from projected census data or local government council data.

Current evidence suggests that the prevalence of inflammatory bowel disease in these groups is at least comparable to that in the White British population, although it is likely that the incidence in second or later generation South Asian communities is significantly higher [14]. On this basis, the proportion of the total populations in each community, receiving biologic therapy or being admitted to hospital with inflammatory bowel disease, would be the same. Therefore, the expected number of patients in each category for each community was calculated and this proportion, compared to the actual proportion using a proportionality statistic. This form of approach to data attained through Freedom of Information researches has been previously described [2].

3. Results

Only two trusts, University Hospitals of Bristol NHS Foundation Trust and Queen Elizabeth Hospital Kings Lynn NHS Foundation Trust, were able to provide data on biologic use. All other trusts provided data on hospital inpatient admissions. In both, Bristol and Kings Lynn, there was equitable access to biologics across the three white communities, namely White British, White Irish and White Other. However, in Bristol where there is a significant Afro-Caribbean community access to biologic therapy was achieved by less than 20% of cases and this was significantly lower than would be expected. Over the five-year period of the study less than five patients from this community received such therapy compared to 450 White patients who were so treated. In both Nottingham and Derby and Burton NHS Trusts Afro-Caribbean patient were treated significantly less often in hospitals than their white counterparts, with figures of 20%, and 21% of expected treatment levels, respectively. In the Kings College Hospital NHS Foundation Trust, the figure was 38% with 2257 Afro-Caribbean patients treated in hospital over the five-year period compared to an expected figure of 6004 ($p < 0.00001$). In the Princess Alexandra Hospital NHS Trust in Essex with a treatment level of 5%, the difference was again very significant ($p < 0.00001$). Although, no significant difference was seen in Birmingham, the actual figure for treated Afro-Caribbean patients was half the expected figure (Table 1).

Table 1. Hospital Admission Statistics and Biologic Use in the Management of Inflammatory Bowel Disease between 2014–2018 in Selected NHS Trusts with significant Black and Ethnic Minority (BEM) Populations in England.

	White British	White Irish	White Other	White	Afro-Caribbean	Asian
Wye Valley NHS Trust						
In-Patient Admissions						
Population	172000	750	7200			
Cases of IBD	3368	24	112			
Expected Cases of IBD	3368	15	141			
Proportion statistic		1.46	−1.8			
Significance		n.s.	n.s.			
University Hospitals of Bristol NHS Foundation Trust						
Use of Biologics						
Population	334,000	3900	22000	360000	19000	
Cases of IBD	429	5	16	450	<5	
Expected cases of IBD	429	5	28	450	24	
Proportion statistic			1.8		−3.78	
Significance		n.s.	n.s.		$p < 0.002$	
Queen Elizabeth Hospital King's Lynn NHS Foundation Trust						
Use of Biologics						
Population	136,000	444	3700			
Cases of IBD	165	3	8			
Expected Cases of IBD	165	1	5			
Proportion Statistic		−1	−0.8			
Significance		n.s.	n.s.			
Croydon Health Services NHS Trust						
In-Patient Admissions						
Population	172,000	5400	2300	180000	60,500	
Cases of IBD	1475	63	168	1706	230	
Expected cases of IBD	1475	46	20		573	
Proportion statistic		−1.6	11		−61.4	
Significance		n.s.	$p < 0.0001$		$p < 0.00001$	
Nottingham University Hospitals NHS Trust						
In-patient admissions						
Population				276000	14100	
Cases of IBD				5133	52	
Expected Cases of IBD				5133	262	
Proportion Statistic					9.4	
Significance					$p < 0.00001$	
University Hospitals of Derby and Burton NHS Foundation Trust						
In-patient admissions						
Population				377000	7500	
Cases of IBD				16111	69	
Expected Cases of IBD				16111	321	
Proportion Statistic					−12.9	
Significance					$p < 0.00001$	
University Hospitals of Birmingham NHS Foundation Trust						
Use of Biologics						
Population				622000	78000	
Cases of IBD				94	6	
Expected cases of IBD				94	12	
Proportion statistic					−1.4	
Significance					n.s.	
Kings College Hospital NHS Foundation Trust						
In-patient admissions:						
Population				170000	78500	
Cases of IBD				13003	2257	
Expected cases of IBD				13003	6004	
Proportion Statistic					−42.3	
Significance					$p < 0.00001$	
NorthWest Anglia NHS Foundation Trust						
In-patient admissions						
Population	159000	1500	22000			18000
Cases of IBD	8161	39	305			236

Expected cases of IBD	8161	77	1129		924
Proportion statistic		−3.6	−22.1		−20.5
Significance		$p < 0.0003$	$p < 0.00001$		$p < 0.00001$
The Princess Alexandra Hospital NHS Trust					
In-patient Admissions					
Population	71000	800	2900	2800	2100
Cases of IBD	3710	27	118	8	37
Expected cases of IBD	3710	42	152	146	110
Proportion statistic		−1.8	−2.1	−11.3	−6.1
Significance		ns	$p < 0.03$	$p < 0.00001$	$p < 0.00001$

n.s. = not significant, IBD = inflammatory Bowel Disease.

When hospital inpatient care was considered White Other communities, largely representative of Eastern European migrant workers, were admitted for inflammatory bowel disease management significantly less often in Croydon, Northwest Anglia and the Princess Alexandra Hospital NHS Trust in Essex with admission rates between 12% and 78%. However, there was no evidence of barriers to access for these communities in Wye Valley Trust, University Hospitals of Bristol NHS Foundation Trust or Queen Elizabeth Hospital Kings Lynn NHS Foundation Trust (Table 1).

In Northwest Anglia NHS Foundation Trust patients of South Asian origin, who were largely Pakistani, were four times less likely to be admitted to hospital than members of the White British community, with an admission rate of 26% of the expected value. ($p < 0.00001$, Table 1).

4. Discussion

This study showed that there is clear widespread discrimination in the care of patients with inflammatory bowel disease in the Afro-Caribbean community. It has also shown that similar issues exist in many areas where there are significant Eastern European migrant communities. Support for the validity of the study comes from the data on the Pakistani community in Peterborough, which confirms earlier reports from elsewhere within England [2]. Indeed, the most recent evidence points towards South Asian communities in the UK having a much higher prevalence of inflammatory bowel disease than the White British community [14], and the difference is likely to be even greater than reported here, where it was assumed that the prevalence was the same.

In the UK, there are a number of significant migrant communities. The South Asian and Afro-Caribbean populations are resident and have been present for several generations. The size of the Irish and Eastern European communities varies over time as many members work in seasonal industries, such as agriculture. In Wye Valley approximately one third of Eastern European people are of Polish origin and about one half of Irish people are Travellers. In Kings Lynn, the majority are Polish or Lithuanian. In Peterborough, there is a significant Polish and Italian population. Many Italians are second and third generation residents of the area, their parents and grandparents coming in the 1950s to work in the brick industry. In Harlow, Essex, the majority of the White Other population are Romanian or Polish. Significant migration from the Caribbean started during World War 1 when people came to work in the North East of England in munition factories. From 1948, the *Windrush* generation were employed to work in transport and the NHS. Their descendants together with more recent immigration from Africa compose the Afro-Caribbean populations in areas such as Birmingham, Bristol, South London, Derby and Nottingham. In addition to the Eastern European migrant population there is a substantial South Asian community of Pakistani origin in North West Anglia. Pakistanis first came to Peterborough to work in engineering and the brickyards, especially on unpopular night shifts and many of its current population are second and third generation migrants, who grew up in North West Anglia. All of these communities are currently, and have been, entitled to free care at the point of delivery within the NHS. Issues of insurance cover for state provided treatment and remuneration for the cost of biological therapy are not relevant within the UK. In the case of biologic therapy, its provision by the NHS is mandatory and legally enforceable as a consequence of a Technological Appraisal by the National Institute for Care and Clinical Excellence (NICE) [15].

Clearly, this study has limitations. It depends upon the accuracy of collection of data on ethnicity by Trusts, the ability and competence of the trust employees who compile the data in response to an

FOI request [16]. Estimates of local population sizes, especially of transient migratory communities, such as agricultural and construction workers, is, at best uncertain and often seasonal. Nevertheless, within these limitations, the magnitudes of the difference in access to care by patients with inflammatory bowel disease from these communities and the White British community is far too great to be solely accounted for by such limitations. Indeed, studies such as those from Leicester [3,7], where case notes were reviewed confirm the reality of this problem, as has also been shown in the USA and Canada [1,4–6].

Discrimination in delivery of care has long been recognised in the USA and in the 1990s the American Medical Association recognised "subconscious bias" may be a factor for such clinical practice [17]. More recently, "conscious bias or, more often, unconscious negative stereotyping" has been considered to be the cause [18]. This may also be the explanation in the UK. The existence of "institutional racism", as described by MacPherson (1999) [19] in the *Stephen Lawrence Inquiry*, has also been recognised within the NHS [20]. However, in a study of English Primary Care Trusts, Salway et al. (2016) [21] found that many managers and clinicians within the NHS questioned the reality of discrimination within healthcare, lacked the skills to deal with it and considered it simply a matter of legal compliance. A similar lack of readiness to accept clear evidence of discrimination in the delivery of care to patients with inflammatory bowel disease has been seen amongst trusts in England, despite its source being their own data [22].

As was recently asked: "How is it possible that people with good intentions seeking to do their best can nonetheless, at an aggregate level, create a pattern of care that is so discriminatory?" Williams response was: "Our answer was implicit bias. It's also called unconscious or unthinking discrimination" [23]. Until there is a readiness to accept that discrimination exists in the delivery of care based on ethnicity, it is highly unlikely that there will be any improvements in the service to these communities. It is incumbent on all gastroenterologists to consider their own clinical practice and encourage their hospital units to adopt effective policies that remove discriminatory barriers to good quality care.

5. Freedom of Information Requests

Croydon Health Services NHS Trust F0I 1678
Kings College Hospital NHS Foundation Trust FOI 6174 and 6266
NorthWest Anglia NHS Foundation Trust FOI 2019/0482 and 2019—798
Nottingham University Hospitals NHS Trust NUH 57316
Queen Elizabeth Hospital King's Lynn NHS Foundation Trust Specific response number not issued but results provided by IBD specialist nurse
The Princess Alexandra Hospital NHS Trust FOI 19-513
University Hospitals of Birmingham NHS Foundation Trust FOI 0281 2019/20
University Hospitals of Bristol NHS Foundation Trust UHB 19-507
University Hospitals of Derby and Burton NHS Foundation Trust FOI 19.674 and 19.697
Wye Valley NHS Trust

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ORIGINAL ARTICLE

An Epidemiological Study of Achalasia Among the South Asian Population of Leicester, 1986–2005

Affifa Farrukh · John DeCaestecker · John F. Mayberry

Abstract Achalasia is an uncommon esophageal motility disorder of unknown etiology that predominantly affects people over the age of 50. The overall incidence in this study was 0.89 cases/10^5/year. There was no significant difference in the proportion of South Asian women with achalasia compared to the proportion of men affected in the whole population nor between the male-to-female ratio in the patient group compared to the healthy population. Throughout the twentieth century there have been sporadic attempts to find any etiological link but to date none have been confirmed. However, there is evidence that environmental factors may be important and these are reflected in geographical differences in the distribution of the disease. In this study we were also unable to identify any triggering factor responsible for the development of achalasia.

Keywords Achalasia · Deglutition · Deglutition disorders

Achalasia is an uncommon condition of unknown etiology. There have been a number of suggestions as to what its cause might be, but none have survived rigorous review. For these reasons epidemiological studies of the condition in various populations continue to be justified in the hope that they will generate new hypotheses about the disease's origin and so perhaps allow the development of successful strategies for its prevention. Migrant communities provide a particularly valuable opportunity for looking at potential factors that may play a role in disease development.

In the 1970s a large number of people left East Africa and settled in the Midlands in the UK. As a migrant community they have acquired many of the same diseases that are present among the indigenous population. Examples include inflammatory bowel disease [1], colorectal cancer [2], and breast cancer [3]. The speed with which these conditions become incorporated into the disease pattern of the migrant community can provide some pointers to the role of environmental as opposed to genetic factors in the etiology of a disease. This study was conducted to review the incidence of achalasia among South Asians in the City of Leicester and compare it with the incidence described in a number of studies among the indigenous population [4–6]. The period under review was 1986–2005 and has allowed an assessment of any changes in frequency over that time. One limitation of the study is the absence of any epidemiological data on achalasia of South Asians in either East Africa or the Indian subcontinent.

Methods

Population and Area Concerned

Leicestershire is a large county that contains the City of Leicester and a number of suburban areas as well as rural communities. This study was restricted to the City of Leicester, which has well-defined political and geographical boundaries with detailed population data. These data are collected as part of the national census every decade and are supplemented by local authority data. This study included only those patients who were living within this defined area at the time of diagnosis. This was verified from patients' addresses and postal codes.

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Table 1 Mean incidence of achalasia among South Asians in each quinquennium in the City of Leicester, 1986–2005

Quinquennium	Midyear population	Number of cases	Incidence	95% CI
1986–1990	63,066	2	0.63	0.1–2.3
1991–1995	80,784	2	0.50	0.1–1.8
1996–2000	80,784	3	0.74	0.1–2.2
2001–2005	78,233	7	1.79	0.7–3.7

Patients with achalasia were identified from a range of diagnostic indices and the diagnosis accepted if they met the criteria defined at the beginning of the study, which were based on radiology, endoscopy, and manometry

The population is served by three hospitals and records have been kept intact together with a diagnostic computer-based classification of all inpatients since the early 1980s. Information from these sources was supplemented by computerized records of endoscopies, manometric studies, and a stock transaction list for botulinum toxin kept since 2000. These sources allowed the identification of a group of potential cases of achalasia.

Criteria for Achalasia

From the cohort of patients identified, cases were separated from noncases and considered to have achalasia and accepted into the study if either of the following criteria were fulfilled: (1) radiological and/or endoscopic evidence of a dilated esophagus which was thought to be due to achalasia in the absence of a peptic or malignant stricture or any other obvious cause of dilatation; (2) the characteristic changes of achalasia on motility studies which include loss of primary and secondary peristalsis and the presence of tertiary contractions; the pressure in the lower esophageal sphincter was often raised and showed incomplete relaxation with swallowing.

Medical Records and Patient Data

Patients with Asian surnames were identified and reports reviewed for diagnosis. Of 53 potential cases, 14 were confirmed as having the disease and meeting the residential criteria. Between 1986 and November 2005, six cases of achalasia were identified from the hospital activities analysis record system. An additional eight cases were identified from the manometry records. Other patients who had initially been retrieved from endoscopy and pharmacy records had already been recorded among the two earlier groups.

The following details were noted from patients' files: their name, address, date of birth, sex, age at diagnosis, duration of symptoms, in particular dysphagia, and date of death. With these data it was possible to ensure that patients appeared only once in the analysis.

Details of the population structure for the City of Leicester were obtained from census data and the local authority. An analysis of age and sex was also available. These figures were used to calculate overall incidence and age-specific incidence.

Results

Seven of the 14 patients were identified by barium examination and five by manometry. Five of those identified by barium examination later had manometry which supported the diagnosis in four cases. Achalasia was suggested in one patient through a CT scan performed for other reasons, but it was later confirmed at endoscopy. All seven patients diagnosed after 2000 were identified from the manometry records and none were reported on hospital activities analysis. Prior to that date all cases were identified through hospital admission data.

In achalasia, there is often a long period of dysphagia before diagnosis. Thirteen of the 14 patients suffered from dysphagia but duration of dysphagia was documented in only seven cases. The mean duration of dysphagia in these cases was 23 months (range = 6–60). Other presenting symptoms were weight loss (43%), chest pain (22%), and vomiting (22%). Therefore, the year of diagnosis as defined by the date of manometry or radiology was a crude measure of disease onset and contributed to some of the variation in incidence from year to year.

The average incidence of newly diagnosed South Asian patients with achalasia in Leicester each quinquennium is shown in Table 1. The overall incidence of achalasia was 0.89 cases/10^5 population/year (95% confidence interval [CI] = 0.1–1.5). There was a considerable variation from year to year. There were years in which no cases were diagnosed, whereas in 2001 there was a peak incidence of 3.8 cases/10^5/year based on three cases. The incidence increased with age, reaching a peak among those over 80 years old. (Table 2 and Fig. 1). The mean age at diagnosis of these 14 patients was 54.1 years (range = 22–86).

Five of 14 patients were women. There was no significant difference in the proportion of South Asian women with achalasia compared to the proportion of men affected in the whole population nor between the male-to-female ratio in the patient group compared to the healthy population.

Two of the 14 patients underwent a Heller's cardiomyotomy. Six underwent balloon dilatation with or without botulinum toxin injection and two received botulinum toxin injection only. There was no record of treatment in

Table 2 Distribution of cases of achalasia in Leicester by age groups

Age	Number of cases	Population	Incidence
80–84	2	588	17 (2–61)
70–79	1	2227	2.3 (0.1–12.5)
60–69	2	4764	2.1 (0.3–7.6)
50–59	4	6891	2.9 (0.79–7.4)
40–49	1	12,364	0.4 (0.01–2.3)
30–39	2	12,029	0.8 (0.1–3)
20–29	1	12,518	0.4 (0.01–2.2)

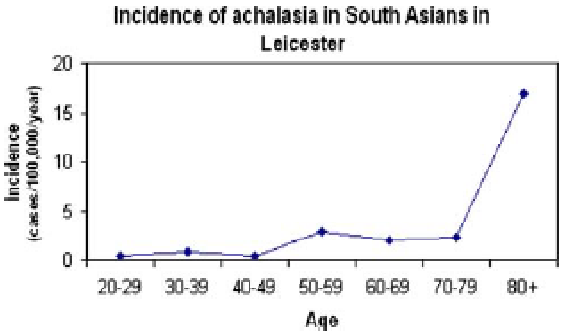

Fig. 1 Incidence of achalasia in South Asians in Leicester

the remaining four patients. Two of the 14 patients in the cohort died and their mean age at death was 68.5 years (range = 63–86).

Discussion

Achalasia is an uncommon disease with an incidence of 0.89 cases/10^5/year in the City of Leicester. This figure is directly comparable to that reported for indigenous populations in Cardiff [4], Nottingham [5], and Edinburgh [6]. All these studies have shown the condition to be more common in men and in people over the age of 50. This study from Leicester has shown figures directly comparable to those for the indigenous population of the UK. There is no evidence of a significant increase in incidence over the quinquennia and the apparent increase during the period 2000–2005 lies generally within the 95% CI. It may also be that the greater use of manometry has played some part in this figure. However, as with the study from central Israel [7], there is no evidence that achalasia is more common in populations of different ethnic or residential backgrounds. This contrasts with the review from Singapore where achalasia was significantly more common among the South Asian population than among Malays and Chinese people [8]. In our study the disease increases with age and this is also consistent with all other reports and has recently been confirmed again in a study from Iceland [9]. It again strongly suggests a role for environmental factors as a cause of the disease, especially among adults. There is a possibility that this increased incidence in those over 50 years of age may be an artifact of lead time to detection, and in the future new techniques such as esophageal ultrasonography may lead to earlier detection of cases. However, the techniques used in this study are still the standard methods of diagnosis [10]. Evidence suggests that the main reason for a delay in diagnosis is misinterpretation of typical findings by the physicians [11].

As with all retrospective studies, this one is limited by the efficiency with which cases are identified and the need to accept a rather broad definition of the disease. These problems can be overcome by use of a prospective methodology. However, the capture/recapture technique used in this study, where no new cases were identified on the third and fourth searches of different diagnostic indices, suggests that most potential cases had been identified. Unfortunately, there are no data on the incidence of achalasia among South Asians in either East Africa or the Indian subcontinent.

In conclusion, achalasia seems to have a similar incidence in a migrant community living in Western Europe with no significant changes in incidence over a 20-year period. The etiology of the disease remains a mystery and this migrant study does not suggest potential environmental factors which could be investigated.

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ORIGINAL ARTICLE

Risk of esophageal cancer in achalasia cardia: A meta-analysis

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Key words
achalasia, meta-analysis, esophageal cancer, risk.

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Abstract

Introduction: The association between cancer of the esophagus and achalasia has long been recognized. However, it has also been recognized that cancers themselves can give rise to achalasia-like syndromes. The risk of developing cancer is also a factor in assessing whether there is a potential role for surveillance in this disease. This paper uses published work to form the basis for a meta-analysis of the risk of developing esophageal cancer among patients with pre-existing achalasia.

Methods: This paper considered cancer risk reported in a range of studies of achalasia published over a 50-year period. Twenty-seven potential studies were identified. In 16 reports, it was possible to extract information on both length of follow-up and duration of achalasia so that person-years duration (PYD) could be calculated. The analysis was stratified between cancers identified in the first year after diagnosis of achalasia and cancers identified in subsequent years.

Results: From pooling the results of 16 studies, the incidence rate of esophageal cancer in achalasia patients was estimated to be 1.36 (95% CI: 0.56, 2.51) per 1000 person years. This is over 10 times higher than the general population incidence rates as reported by the IARC.

Conclusions: Therefore, our meta-analysis shows that achalasia is a major risk factor for the development of esophageal cancer. This is supported by the results from the time-stratified analysis. Incidence of esophageal cancer per 1000 person years was lower in the first year after diagnosis of achalasia than in subsequent years. This is strong evidence against the idea that achalasia may be induced by esophageal cancer instead of vice versa.

Introduction

An association between achalasia and esophageal cancer was first recognized as long ago as 1872.[1] The patient had experienced difficulty with swallowing for 40 years before the tumor developed. Several subsequent studies have suggested that the risk of developing squamous carcinoma of the esophagus for a patient with achalasia is somewhere between 3[18,32] and 30%.[2–4] In 1984, Chuong *et al.* questioned this association, and currently, the American Society for Gastrointestinal Endoscopy does not advocate surveillance in patients with achalasia because there is insufficient data from large well-conducted epidemiological studies.[5] However, there is emerging pressure from some groups to introduce such an approach for the long-term management of this condition.[6]

The first purpose of this meta-analysis of studies conducted over the last 50 years was to establish the magnitude of the risk and to investigate how this changes with time following diagnosis. On the basis of such data, it then becomes possible to consider the potential efficacy of a screening program and the frequency with which endoscopic intervention would be needed for a surveillance program to be effective and from this the likely cost and cost effectiveness of such a program.[7] Such a study will not address the issue of the effectiveness of endoscopists in detecting early lesions—an area in which gastroenterologists and specialist pathologists have largely failed to prove themselves in the field of ulcerative colitis.[8] However, in the case of achalasia, because of the enlarged nature of the esophagus, patients usually develop symptoms late and therefore present only at a stage of advanced malignancy, and so, the overall prognosis is poor. In this study, there was an opportunity to assess the magnitude of the risk of cancer and to consider whether surveillance could be of value. This needs to also be considered within the legal terms of what such a program would offer patients and at what risk.[9]

Methods

A literature review was carried out of both the English and non-English language literature using Medline. Twenty-seven potential studies were identified where patients with achalasia had been followed up and subsequent cancer incidence had been reported. Each paper was then reviewed, and their references were checked to identify further studies. Where possible, information was extracted on both length of follow-up and duration of achalasia so that person-years duration (PYD) could be calculated. In addition, information was extracted on the number of cancers and whether the cancer developed within the first year after diagnosis of achalasia or in subsequent years.

Only 16 of the 27 studies identified provided sufficient information to establish the total number of cancers detected and for overall PYD to be calculated. Sufficient detail was provided in 12 of the 16 studies to identify whether cancer was diagnosed in the first year after diagnosis of achalasia or in later years. Figure 1 gives a break down of the data extraction process. Many of the studies, especially when stratified, reported zero cases of cancer. A continuity correction of 0.5 was added to the zeros so that a meta-analysis model in which the log incidence rate was assumed to be approximately normally distributed could be applied. As an alternative to using a continuity correction, the data were also modeled directly using a Bayesian Poisson regression meta-analysis, which has the advantage of allowing all the uncertainty associated with the between-study heterogeneity to be included.

The analysis was stratified between cancers identified in the first year after diagnosis of achalasia and cancers identified in subsequent years. This was because it was important to identify cases in which the cancer may have developed prior to a diagnosis of achalasia or where patients had been inappropriately diagnosed with achalasia when, in fact, they were suffering from esophageal cancer. Stratifying the analysis also enabled some assessment of how the risk of cancer changes with time since diagnosis.

Results

Table 1 lists the characteristics of the studies included in the meta-analyses. Most of the studies used were carried out in Europe, although studies from the United States, South America, and Australia were also included. Table 2 documents the studies that were excluded and the reasons for doing so. The time period covered by the studies varied widely; some started as early as the 1930s, while others ran into the 1990s. All studies covered a time period of at least 10 years. The size of the studies also varied, with the number of achalasia cases investigated ranging from 43 to 1062. Mean age of study participants was not always reported, but it has been included in Table 1 where the figures were available. Chagas disease is an infective disease comparable to achalasia but only found in Latin America. Two of the studies in this meta-analysis were carried out in Argentina and Chile, where the achalasia cases followed up could, in fact, be potentially misdiagnosed Chagas cases. Fortunately, both these studies tested all participants for Chagas disease to try and identify any such cases. The Argentinian study found only 2 cases of Chagas among their 242 patients, whereas the Chilean study found 15 cases of Chagas among the 100 patients they followed up. As these are a small proportion of the study samples, and the data for the true achalasia patients could not be separated out from the study results, these studies, and consequently a few Chagas cases, were retained in the meta-analysis.

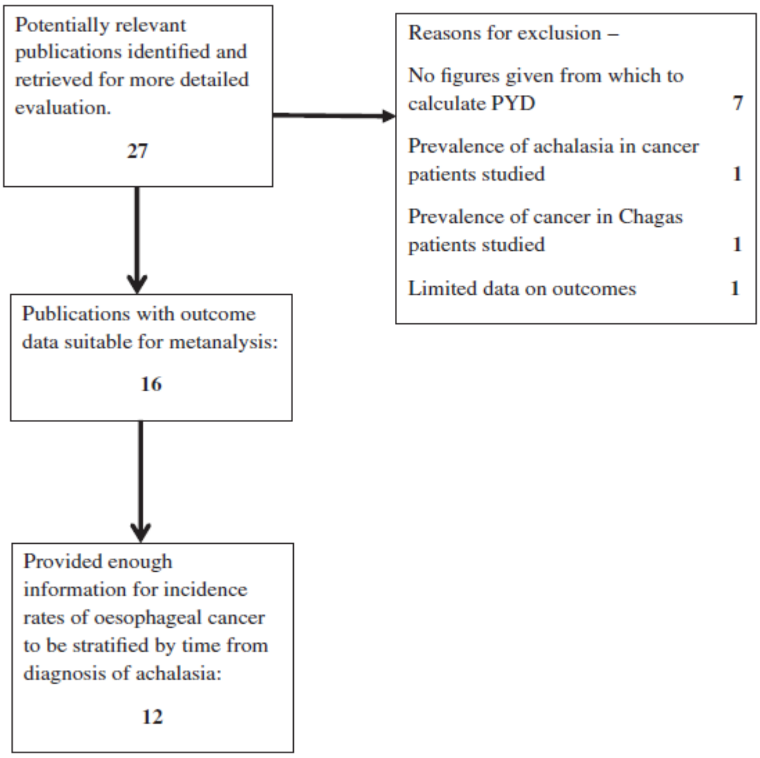

Figure 1 Flow diagram.

Table 1 Characteristics of studies used in the meta-analysis

Study	Period	Country	Number of Cases (cancers)	Mean age (SD)	Age range
Aggestrup *et al.*[10]	1949–1964	Denmark	146 (10)	46†	4–83
Arber *et al.*[11]	1973–1983	Israel	162 (0)	47.7 (18.3)	2–85
Barrett[12]	1935–1964	England	120 (7)	—	4–84
Chuong *et al.*[5]	1971–1981	USA	100	53.1	41–89
Corti *et al.*[13]	1970–1990	Argentina	242 (8)	61.3	41–76
Csendes *et al.*[14]	1973–1987	Chile	100 (3)	42	13–18
Ellis[3]	1933–1948	England	69 (7)	—	12–59
Malthaner *et al.*[15]	1964–1983	Canada	52 (0)	43.7	22–67
Mattioli *et al.*[16]	1955–1991	Italy	185 [28]	41.5	4–76
Meijssen *et al.*[17]	1973–1988	Netherlands	195 (3)	52	—
Perrachia *et al.*[18]	1967–1988	Italy	244 (1)	—	—
Pierce *et al.*[19]	1954–1969	USA	110	—	—
Russell *et al.*[20]	1979–1989	Australia	43	49†	13–86
Sandler *et al.*[21]	1964–1989	Sweden	1062 (24)	57.2	—
Streitz *et al.*[22]	1970–1992	USA	241 (3)	—	—
Wychulis *et al.*[23]	1935–1967	USA	1318 (7)	—	—

†Median.

Table 2 Studies not included in the meta-analysis of cancer risk in achalasia

Author	Date	Country	Cases	Mean age	Range	Follow-up (months)	Cancers
Overlap with studies in analysis							
Ruffato *et al.*[24]	1978–2002	Italy	174	57 (median)	7–83	93	4
Leeuwenburgh *et al.*[25]	1975–2006	Netherlands	448	51	4–92	107	15
Zaninotto *et al.*[26]	1980–1992	Italy	228			220	4
Other studies							
Khan *et al.*[27]	1987–2003	Pakistan	300	40	17–72	192	0
West *et al.*[28]	1971–1994	Netherlands	125			144	6
Brucher *et al.*[29]	1982–1998	Germany	124	49	9–91	67	4
Harris *et al.*[30]	1991–1998	England	40	38 (median)	15–84	17	3
Gugulski *et al.*[31]	1961–1992	Poland	252	41	15–81	138	0
Liu *et al.*[32]	1979–2000	China	176	32.9		168	3

Of the two methods used for fitting the meta-analyses models, it was thought that the Bayesian approach, as opposed to the normal approximation, would give the most accurate results. The results from the normal approximation would be slightly inflated due to the use of a continuity correction, and the Bayesian model also has the advantage of allowing for all the uncertainty associated with the between-study heterogeneity. Therefore, it is the results from the Bayesian model that are reported in Table 3. The drawback of the Bayesian model is that the confidence intervals of estimates from individual studies are shrunken as the model draws information from all the studies to estimate the confidence intervals. Therefore, for the purposes of the forest plot (Fig. 2), the normal approximation model was used. Figure 2 shows the forest plots. Sixteen studies had information on number of esophageal cancer cases for the whole time period after diagnosis of achalasia. For 12 studies, the cancer cases could be divided into those occurring in the first year after diagnosis of achalasia and those occurring in subsequent years. Generally, there was a higher incidence rate of esophageal cancer in subsequent years. Therefore, risk of esophageal cancer was increased in patients who had lived with achalasia for more than 1 year.

Table 3 reports the results of the Bayesian meta-analysis. The pooled incidence rate of esophageal cancer in achalasia patients was 1.36 (95% CI: 0.56, 2.51) per 1000 person-years. When results were stratified by time since diagnosis of achalasia, it could be seen that incidence rates were lower in the first year after diagnosis when compared to subsequent years, 0.71 (95% CI: 0.00, 4.71) compared to 1.55 (0.60, 2.53) per 1000 person-years, respectively. Table 4 reports the population incidence rates of esophageal cancer in regions of the world where the studies used in this meta-analysis were based. The confidence intervals for the pooled estimates for all years and > 1 year. do not include any of the population estimates; this shows that the incidence of

Table 3 Incidence of esophageal cancer in patients with achalasia, estimated from the Bayesian Poisson regression meta-analysis

Data used	Studies (*n*)	Incidence rate (95% credibility intervals)
All years	16	1.36 (0.56,2.51)
<Year 1	13	0.71 (0.00, 4.71)
>Year 1	13	1.55 (0.60, 2.53)

Rates are per 1000 person-years.

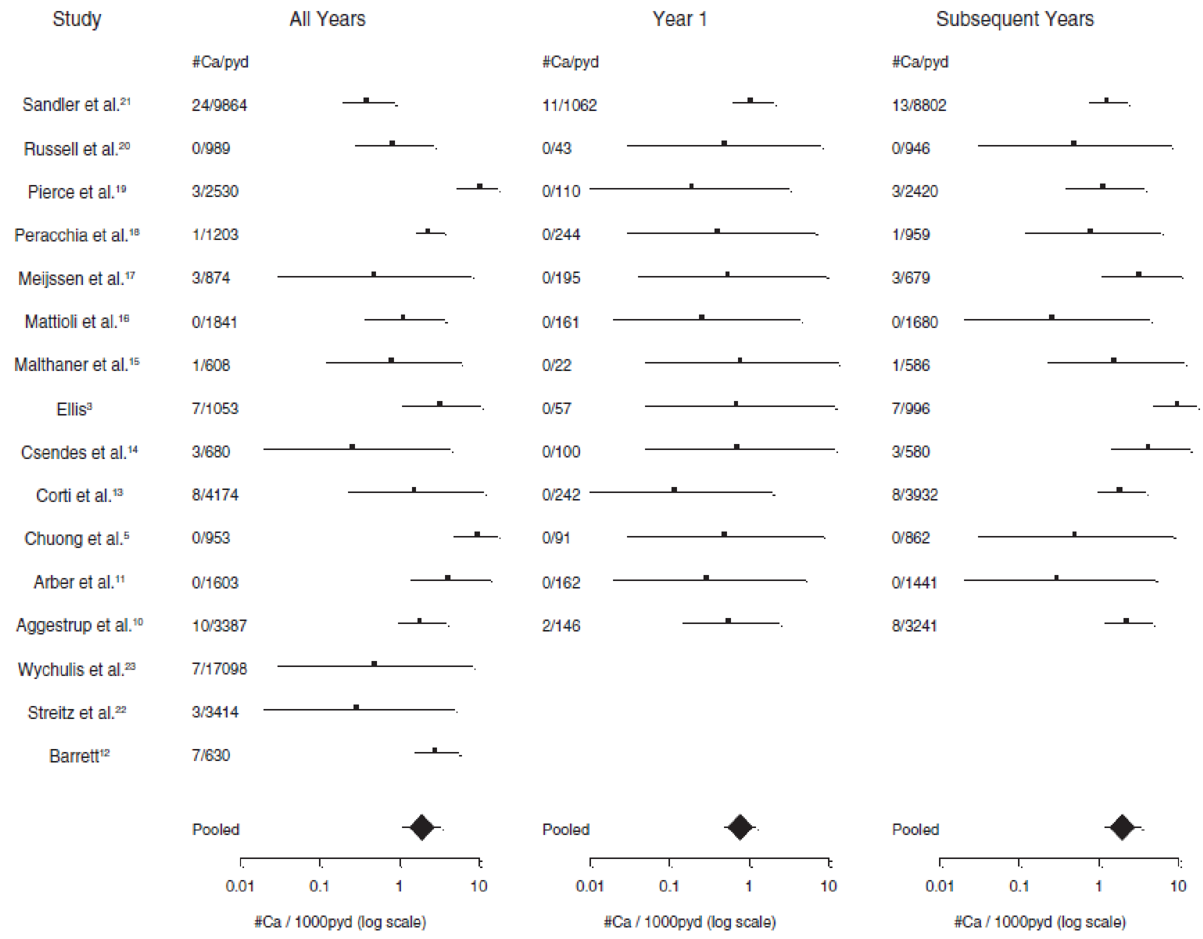

Figure 2 Meta-analysis of esophageal cancer occurrence stratified by time since diagnosis.[1–3,6–8,12,22–26,29,30,32]

esophageal cancer in the achalasia patients included in this meta-analysis were significantly higher than those of general populations ($P < 0.05$). The pooled incidence for <1 year after diagnosis of achalasia was not significantly different from the population estimates reported in Table 4. This is probably due to limited data resulting in wide confidence intervals.

Discussion

From pooling the results of 16 studies, the incidence rate of esophageal cancer in achalasia patients was estimated to be 1.36 (95% CI: 0.56, 2.51) per 1000 person-years. This is over 10 times higher than the general population incidence rates as reported by the IARC. Therefore, our meta-analysis shows that achalasia is a major risk factor for the development of esophageal cancer. This is supported by the results from the time-stratified analysis. Incidence of esophageal cancer per 1000 person-years was lower in the first year after diagnosis of achalasia than in subsequent years. This is strong evidence against the idea that achalasia may be induced by esophageal cancer instead of vice versa. The data do not allow an analysis of whether treatment of achalasia reduces cancer risk, although risk seems to increase with duration of disease. Until this question is addressed, it will not be possible to advocate routine surveillance.

Table 4 Incidence of cancer of the esophagus per 1000 person-years

Region	Male	Female
World	0.09	0.04
Northern Europe	0.07	0.07
Northern America	0.06	0.02
South America	0.06	0.02

Figures from GLOBOCAN.[32]

It is important to remember that the achalasia patients in this meta-analysis may not be directly comparable to general populations. The majority of the studies included had a mean age of participants in the 40s or 50s. This is fairly comparable to a westernized population, although it is accepted that age is a possible confounder. Unfortunately, as age was poorly reported in these studies, it was impossible to calculate standard morbidity ratios, which would have accounted for any confounding effects of age.

Incidence rates of esophageal cancer have changed over time, and in this study, we have compared incidence in patients from as early as the 1930s with the general population figures from

1990. Although esophageal cancer is on the increase,[32] this cannot explain why incidence rates have been found to be so much higher in these studies of achalasia patients.

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Original observational study on disparate treatments for achalasia experienced by patients of white British and South Asian ethnicity

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Background: To date, there have been no studies which have considered whether treatments for achalasia are delivered equitably to different communities within a multi-ethnic society.

Methods: Thirteen Trusts across England were sent Freedom of Information requests to provide information on admissions for achalasia between 2010 and 2019. Data were requested for patients of White British and South Asian ethnicity together with treatment details. Trusts which provided complete data were distinguished from those quoting numbers as <10 or <5 and results analysed separately. Treatment types were compared and correlation with deprivation sought.

Results: In those Trusts which provided a detailed response there was a significant difference in the pattern of treatment between White British and South Asian patients. (χ^2=9.56, P<0.05). 27% of South Asian patients underwent surgical management in the form of a myotomy compared to 19% of White British patients. South Asian patients were significantly more likely to undergo a POEM procedure than White British patients (z=−3.12, P<0.01). Confirmation of a different pattern of treatment was seen in the second group of Trusts where there was a maximum of 865 admissions for treatment of achalasia. When the possible maximum number of patients treated during the decade was considered, significance was comparable (χ^2=7.59, P<0.05). If the minimum number of admissions of 736 was considered, then χ^2=15.77, P<0.001. Deprivation was separately correlated with number of procedures per patient for both White British ethnicity (r_s=0.733, P<0.05) and South Asian ethnicity (r_s=0.686, P<0.05), indicating this was not the cause of disparate treatment.

Conclusions: Patients with achalasia, who are South Asian, receive a different pattern of treatment to White British patients. They were 8% more likely to undergo a surgical form of management and 8% less likely to receive Botulinum toxin therapy. They are more likely to have a POEM procedure in inexperienced centres. In deprived communities both South Asian and White British patients are less likely to receive multiple therapies for long-term management of the disease.

Keywords: Achalasia; ethnicity; treatment; discrimination; South Asian

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Introduction

Achalasia is an uncommon condition of unknown aetiology with an incidence in the United Kingdom (UK), which ranges from 0.5 to 2.0/10^5 population/year (1-6). The only study which has considered its incidence in the South Asian community has placed it at the higher end of this range (5). There has been a South Asian community in the UK for well over one hundred years, but it significantly expanded in the 1970s with the expulsion of peoples from East Africa (7). Current estimates suggest that there are more than 3 million South Asian people in the UK, making up 5% of the population. There is a growing recognition that patients from this community receive poorer care than White British patients across a wide spectrum of diseases (8-14). In addition, there is evidence that patients from this community are offered less choice as to which treatment they wish to receive, compared to White British patients (12). However, there have been no studies amongst any ethnic minority communities on access to treatments for achalasia in the UK, or elsewhere in the world, or on the nature of treatments offered to them. The purpose of the present investigation was to consider which treatments were offered to South Asian patients and compare it with those offered to White British patients. The study was conducted in areas where there were both significant White British and South Asian communities composed of people of either Pakistani, Indian, or Bangladeshi origin.

Traditionally treatment for achalasia was either by pneumatic dilatation or a Heller's myotomy. This form of surgery is now usually performed as a laparoscopic procedure, and can be robot-assisted (15). The emergence of its endoscopic equivalent, a peroral endoscopic myotomy (POEM) procedure, has widened the choice of therapies available to patients, as has the use of botulinum toxin to temporarily paralyse the lower oesophageal sphincter (16). However, in a study of the advice given by surgeons to patients on choice of therapy, there was a clear preference for either a Heller's myotomy or a POEM procedure (17). Duration of benefit from the intervention and long-term cost effectiveness would support such advice (18-20). In 2019 a meta-analysis identified 12 cohort trials which compared laparoscopic and endoscopic myotomy and reported similar outcomes for improvement of dysphagia and post-procedure reflux, but with a shorter hospital stay for POEM (21). This contrasts with the findings of a meta-analysis of 19 studies, including 5 which were randomised controlled. In this analysis dysphagia outcomes were better for patients who had a POEM procedure, but gastro-oesophageal reflux was worse (22). When POEM was compared with pneumatic dilatation in a meta-analysis of 7 studies overall risk of complications was greater and gastro-oesophageal reflux was again worse with POEM (23). Indeed, Nurczyk and Patti have drawn attention to the risk of developing Barrett's oesophagus and even an oesophageal cancer following POEM, although the latter complication may reflect the underlying risk of the disease (24,25). In contrast to professional guidance, when patients were given comprehensive advice and clearly involved in the decision-making process, 63% chose pneumatic dilatation, botulinum toxin therapy or no treatment, rather than a surgical intervention (26). Recommendation 2.8 of the European Guideline on Achalasia specifies that: "*Treatment decisions in achalasia should be made based on patient-specific characteristics, the patient's preference, possible side effects and/or complications and a center's expertise.*" (16).

The issue of expertise is important when considering patient choice. In a study from Johns Hopkins, USA, it was considered that the minimum number threshold cases required for an expert to reach a plateau when performing POEM was 13 (27). The figures from a different single centre study in Tianjin, China suggested the number was 25 cases (28) and in Shanghai 100 cases were required to decrease the risk of technical failure, adverse events and clinical failure (29). In Mineola, New York, efficiency was achieved after 40 POEMs and mastery after 60 (30). For a condition with the rarity of achalasia these are large numbers.

The right of a patient to make the decision as to which treatment they wish to receive, including poorer options, has been enshrined in law through the decision of the Supreme Court in *Montgomery v Lanarkshire* (31). In the case of achalasia and the POEM procedure, patients are entitled to know where the endoscopist is on his or her learning curve. Such information is particularly important where the first language of the patient and doctor are different. A large study in general practice in the UK has shown the importance of a concordant language for effective communication and patient satisfaction (32). Recent studies on health outcomes in various ethnic communities in the UK have suggested that some element of these differences may be due to social deprivation rather than to disparate or discriminatory care (33-35). As Krieger has pointed out, when social deprivation is not responsible for differences in health care practices the role of discrimination must be considered (36). The purpose of the current study was to examine patterns of treatment experienced by South Asian and White British patients and, if there was a difference, to consider whether social deprivation had played a part.

The method chosen to identify patients for inclusion in the study was that of Freedom of Information requests directed to specific Trusts, serving communities with significant South Asian populations. Such an approach has been used in earlier studies, which have investigated aspects of care (8,11). Fowler *et al.* have drawn attention to the transparency associated with such data requests and this is particularly important where questions of potentially disparate care to different ethnic groups arises (37). There are, however, issues with how an agency responds to a request for information (38), including resistance to release of data (39).

We present the following article in accordance with the MDAR checklist (available at http://dx.doi.org/10.21037/aoe-20-72).

Methods

This study was conducted in accordance with the Declaration of Helsinki (as revised in 2013). Requests for information on the number of treatments each year between 2010 and 2019 were sent to Trusts which served areas with a significant South Asian population. These included: (I) Luton (Bedfordshire Hospitals NHS Foundation Trust; (II) Bradford (Bradford Teaching Hospitals NHS Foundation Trust); (III) Blackburn (East Lancashire Hospitals NHS Trust); (IV) Slough (Frimley Health NHS Foundation Trust); (V) Southhall, London (London North West University Healthcare NHS Trust); (VI) Peterborough (North West Anglia NHS Foundation Trust); (VII) The Acute Pennine NHS Trust of Oldham, Rochdale and North Manchester (Northern Care Alliance); (VIII) Salford (Northern Care Alliance); (IX) Sandwell and West Birmingham (Sandwell and West Birmingham NHS Trust); (X) Wolverhampton (The Royal Wolverhampton NHS Trust); (XI) Birmingham (University Hospitals Birmingham NHS Foundation Trust); (XII) Leicester (University Hospitals of Leicester NHS Trust); (XIII) Nottingham (Nottingham University Hospitals NHS Trust).

Each Trust was sent a Freedom of Information request and was asked to provide data on hospital admissions between 2010 and 2019 for: (I) Heller's myotomy; (II) Endoscopic pneumatic dilatation; (III) Endoscopic injection of botulinum toxin; (IV) Endoscopic oesophageal myotomy (POEM procedure).

The response was to be broken down by ethnicity, namely: (I) White British; (II) Pakistani; (III) Indian; (IV) Bangladeshi.

Responses were analysed in terms of total number for each procedure into two categories, namely White British and South Asian (Pakistani, Indian and Bangladeshi combined). Responding Trusts were divided into two groups—those who provided specific answers in relation to the Request and those who stated that <5 or <10 patients had been admitted in one of the categories. The reason given for such responses by the latter group of Trusts was that a more specific answer might allow identification of a patient, despite the fact that no personal characteristic other than ethnicity was requested.

The pattern of management in the two ethnic communities was compared using a χ^2 with 2 or 3 degrees of freedom, as appropriate. Analysis was performed separately for the Trusts providing complete data and those stating that less than 5 or 10 patients had been treated in a category. In this latter group the analysis was performed on the basis that 4 or 9 patients had been treated, although the actual number might have been between 0 and 3 or between 0 and 8.

In order to make an assessment of the quality of the Freedom of Information data, the expected number of cases for each community was estimated on the basis of an incidence of achalasia of $1/10^5$ population/year. It was also assessed using the highest reported incidence figure for the UK of $2/10^5$/year (6). This latter figure is similar to that described earlier for the South Asian population of $1.8/10^5$/year (5). Using these data estimated numbers of treatments for achalasia were derived for each Trust. The populations relevant to NorthWest London and Frimley Park NHS Trust were unclear and so estimates were not made for those Trusts. There are significant limitations to this approach which include: (I) the population estimates for the area served by each Trust was derived from Census data and does not reflect referral into specialist units from outside the normal catchment area; (II) the catchment area for Trusts does not correspond specifically to Census enumeration areas and the Census data used were based on information collected in 2010; (III) there is one earlier study (5), based on actual case review, which indicates that the incidence of achalasia in the South Asian community may be higher than the British White population, although a more recent study (6) based on secondary diagnostic coding data alone did not confirm this.

These data were compared with a Student's *t*-test to assess whether there was any difference in the number of treatments per patient by ethnicity. They were also examined in relation to the Index for Multiple Deprivation published in 2019 for each area studied using Spearman's Rho correlation coefficient.

Results

A detailed response was provided by Leicester, Wolverhampton, Luton, Sandwell and West Birmingham, Birmingham and Bradford, where there had been 1,198 admissions for treatment of achalasia between 2010 and 2019. East Lancashire, Northern Alliance, Frimley Health NHS Foundation Trust, London North West University Healthcare NHS Trust and Peterborough (North West Anglia NHS Foundation Trust were in the second group with categories of treatment with <5 patients and <10 patients. Nottingham University Hospitals Trust was unable to provide any relevant data.

In those Trusts which provided a detailed response there was a significant difference in the pattern of treatment between White British and South Asian patients (χ^2=9.56, with a sample size of 1,198, three degrees of freedom and P<0.05; *Table 1*). 27% of South Asian patients underwent some form of surgical management in the form of a Heller's myotomy or a POEM procedure compared to 19% of White British patients (*Table 2*). South Asian patients were also 6% less likely overall to receive Botulinum toxin therapy than White British patients (*Table 2*). Within individual Trusts, the different pattern of treatment reached significance in Bradford and Sandwell and West Birmingham (*Table 1*). However, the pattern in Sandwell and West Birmingham was the reverse of the national trend.

Confirmation of the different pattern of treatment in the two communities is also seen in the results from the second group of Trusts where there was a maximum of 865 admissions for treatment of achalasia between 2010 and 2019 (*Table 3*). When the possible maximum number of patients treated during the decade was considered the level of significance was comparable with χ^2=7.59, with a sample size of 865, two degrees of freedom (P<0.05). If the minimum number of admissions of 736 is considered, then χ^2=15.77, with a sample size of 736, two degrees of freedom gave (P<0.001).

In this study, 5 South Asian patients underwent a POEM procedure compared to 17 White British patients. The rate for South Asian patients undergoing a POEM procedure was significantly higher than White British patients. Where details were provided for all forms of treatment z=−3.12, P<0.01. However, the differences remained significant when

Table 1 Procedures to treat achalasia between 2010 and 2019 in trusts which provided a detailed breakdown of their practice

Trust	Hellers myotomy		Endoscopic pneumatic dilatation		Endoscopic botulinum toxin injection		POEM		Sample size	χ^2	Degrees of freedom	P
	White British	South Asian	White British	South Asian	White British	South Asian	White British	South Asian				
Leicester	71	14	256	39	146	11	0	0	537	5.76	2	NS
Wolverhampton	21	4	26	5	6	0	0	0	62	0.0002	1	NS
Luton	2	1	137	16	18	0	0	0	174	1.59	1	NS
Sandwell & West Birmingham	7	1	13	16	2	0	1	0	40	4.6	1	<0.05
Birmingham	51	7	54	8	4	2	8	4	138	5.28	3	NS
Bradford	31	14	140	14	33	11	3	1	247	15.85	3	<0.001
Total	183	41	626	98	209	24	12	5	1,198	9.56	3	<0.05

χ^2=9.56, with a sample size of 1,198, three degrees of freedom and P<0.05. POEM, per oral endoscopic myotomy; NS, not significant; p, probability.

Table 2 Types of treatment offered to patients with achalasia in those trusts providing a detailed breakdown of numbers

Treatment type	White British	South Asian
Heller's myotomy	17.8%	24.4%
Pneumatic dilatation	60.8%	58.3%
Botulinum toxin	20.3%	14.3%
POEM	1.2%	3.0%

POEM, per oral endoscopic myotomy.

Table 3 Procedures to treat achalasia between 2010 and 2019 in trusts which provided a breakdown of their practice, where precise numbers were not given if less than 5 patients had been treated in any category

Trust	Hellers myotomy		Endoscopic pneumatic dilatation		Endoscopic botulinum toxin injection		POEM	
	White British	South Asian	White British	South Asian	White British	South Asian	White British	South Asian
East Lancashire	<44	2	<59	<12	129	<20	0	0
Salford	53	<10	13	0	34	0	0	0
Acute Pennine	24	<20	<10	0	64	<20	0	0
Frimley	<5	<5	<5	<12	86	<5	5	0
North West London	0	0	0	0	28	8	0	0
North West Anglia	33	<15	110	<15	25	<15	0	0
Total (maximum)	157	48	194	36	366	64	5	0
Total (minimum)	134	25	175	15	366	21	5	0

For maximum number of cases χ^2=7.59, with a sample size of 865, two degrees of freedom and P<0.05. For minimum number of cases χ^2=15.77, with a sample size of 736, two degrees of freedom and P<0.001. POEM, per oral endoscopic myotomy; ns, not significant; p, probability.

centres who provided ranges of treatment were included (z=−2.14, P<0.03). Similarly, South Asian patients were more likely to undergo a Hellers myotomy than White British patients (z=−2.04, P<0.05). There were no significant differences in the rates for pneumatic dilatation or use of botulinum toxin.

One published study has considered the types of treatment undergone by patients in India at 5 referral centres (40). Of 252 Indian patients 122 had had a Heller's myotomy, 76 pneumatic dilatations, 32 a POEM procedure and 22 treatment with Botulinum toxin. This pattern of treatment was significantly different to that received by South Asian patients (χ^2=47.9, with a sample size of 420, two degrees of freedom P<0.001) and White British patients (χ^2=208, with a sample size of 1,282, two degrees of freedom P<0.001) in this study. There have been no comparable studies from Pakistan or Bangladesh.

Table 4 lists the number of procedures per patient over the 10-year period. It ranges from 1 to 12.4, when an incidence of $1/10^5$/year was used as the basis of the calculation for the expected number of cases and from 0.5 to 6.5 at the higher incidence rate. At the lower incidence rate the number of procedures was positively correlated with the Index of Multiple Deprivation Spearman's Rho r_s=0.72, P (two tailed) <0.05. At the higher incidence rate the correlation ranged between r_s=0.7, P (two tailed) <0.05 and r=0.75, P (two tailed) <0.05. Deprivation was separately correlated with number of procedures per patient for both White British ethnicity [r_s=0.733, P (two tailed) <0.05] and South Asian ethnicity [r_s=0.686, P (two tailed) <0.05]. The number of procedures per patient was not significantly different between White British and South Asian ethnicity. In more deprived communities both White British and South Asian patients were less likely to undergo procedures

Table 4 Estimated number of cases of achalasia over period 2010–2019

Geographical location	Incidence $1/10^5$/year		Incidence $2/10^5$/year (White British)	Incidence $1.8/10^5$/year (South Asian)	Number of procedures per patient at lower incidence rate	Number of procedures per patient at higher incidence rate	Index of multiple deprivation
	White British	South Asian					
Leicester	71	15	142	27	6.2	3.2	25
Wolverhampton	18	3	36	5	3	1.5	21
Luton	11	6	22	11	10.2	5.3	69
Sandwell & West Birmingham	29	12	58	22	1.0	0.5	12
Birmingham	57	24	114	43	1.7	0.89	9
Bradford	33	12	66	22	5.5	2.81	26
East Lancashire	26	6	52	11	8.1	3.37–4.16	17
Salford & Acute Pennine	214	22	428	40	1	0.45–0.52	18 & 37
North West Anglia	15	2	30	44	12.4	5.2–6.5	71

The estimated number of cases was based on population data derived from the 2011 Census and an incidence rate of $1.0/10^5$ population/year and for the highest reported incidence rates in the UK. The populations relevant to North West London and Frimley Park NHS Trust were unclear and so estimates were not made. At the lower incidence rate the number of procedures was positively correlated with the Index of Multiple Deprivation [Spearman's Rho r=0.72, P (two tailed) <0.05]. At the higher incidence rate the correlation ranged between [r=0.7, P (two tailed) <0.05] and [r=0.75, P (two tailed) <0.05]. Deprivation was separately correlated with number of procedures per patient for White British ethnicity [r=0.733, P (two tailed) <0.05] and South Asian ethnicity [r=0.686, P (two tailed) <0.05]. The number of procedures per patient was not significantly different between White British and South Asian ethnicity.

for treatment of achalasia.

Discussion

Patients with achalasia, who are South Asian, received a different pattern of treatment to White British patients. They were 8% more likely to undergo a surgical form of management in the form of a Heller's Myotomy or POEM procedure and 6% less likely to receive Botulinum toxin therapy. In more deprived communities both South Asian and White British patients were less likely to receive multiple therapies for long-term management of the disease and with rates of treatment below 1 for the estimated number of cases, by implication, achalasia is not being diagnosed at the expected frequency either. Such variations in patterns of treatment between ethnic groups have been described for various conditions in the UK. For example, Black, South Asian, and Eastern European patients with inflammatory bowel disease were less likely to receive biologic therapy than White British patients (8,9,11). This has been demonstrated across a number of Trusts and at various times using different methodologies (8,9,11). In the management of breast cancer, Black African women were less likely to have either surgery or hormone treatment and more likely to be simply offered chemotherapy, whilst Pakistani women were less likely to be offered radiotherapy or hormone treatment than White women (12). In the UK ethnic minority patients on the renal transplant register continue to be less likely to receive a donor organ than White patients (41). In the field of mental health, Black service users tend to be given injectable depot treatments rather than offered tablets, family or cognitive behavioural therapy or copies of care plans (42). In general, patients from ethnic minorities have reduced access to expensive treatments and are offered less choice of therapies. In the present study, differences in treatment patterns are again seen. However, the reasons for the differences are less clear. For example, the greater likelihood of undergoing a POEM procedure in a unit with limited experience raises the question as to why. Were the patients provided with comprehensive information which they understood? Was that information in a language with which they were at ease? This study does not provide an answer, but it is probable that issues with effective communication may have played a part. POEM was only performed in 22 patients across all centres, with a maximum of 5 in any one centre. Published studies would, therefore, suggest that none of the operators had reached a level of efficiency or mastery of the procedure (27-30). Questions, therefore, remain as to why South Asian patients were 4.5 times more likely to undergo a procedure in which the clinicians lacked experience and were still on the early part of their learning curve. However, the fact that South Asian patients were more likely to undergo a Heller's myotomy also raises the possibility that clinicians guided patients towards what they considered was the best option without adequate and appropriate discussion (17). It is clear from the analysis that these differences cannot be attributed to social deprivation and further investigation into the reasons would need to include qualitative assessments amongst providers and consumers.

Harvey assessed the durability of outcomes of various forms of treatment for achalasia in the UK and found that for a single initial treatment at 9 years follow-up was 19.23%, 43.97%, 85.78% for injection, dilatation, and surgical treatment respectively (19). For many years, the selection of treatment strategy was based primarily on the experiences of the experts. However, there have been few studies on the role of patient choice in decisions on form of therapy. In a Canadian study of 83 patients, 37% chose to have a Heller's myotomy, 30% a pneumatic dilatation and 4% Botulinum therapy (26). In the first year following diagnosis 29% of patients chose not to have any treatment (26). A report from the UK has shown that regardless of age the majority of patients were offered a Heller's myotomy as first line treatment, without evidence of detailed discussions with the patients or at Multi-disciplinary Team meetings (17). In Canada, Panaccione *et al.* reported that in the long-term botulinum toxin therapy is more costly than pneumatic dilatation (43). An earlier study from the USA had similar results (44). However, this American study showed that laparoscopic oesophagomyotomy was the most effective treatment option, but was not cost-effective, because of its initial high cost. In a meta-analysis botulinum toxin was the treatment modality with the worst outcomes, but POEM exhibited excellent results for all achalasia subtypes (18). On this basis, it would appear, on the surface, that overall South Asian patients may be receiving more effective treatment than White British patients, in the form of Heller's myotomy or POEM. However, this fails to take account of the inexperience of the providers in performance of POEM procedures. The question then arises as to why this might be the case. The answer may lie in the attitudes of the health provider. There is evidence to support the hypothesis that provider beliefs about patients and provider behaviour during encounters are independently influenced by patient ethnicity (45). In the case of elderly South Asian patients, there is extensive evidence supporting such a view with failures to provide adequate information in an appropriate language for informed decision making (46).

With the advent of *Montgomery v Lanarkshire*, the importance of providing patients with comprehensive and comprehensible information about treatment choices has become central to the care of people of all communities (31). Clinicians, in particular surgeons, are likely to advocate a laparoscopic Hellers myotomy or POEM (17). In the context that, when offered a choice, 63% of patients chose other forms of treatment or no treatment at all (18), the pattern of treatment seen in the South Asian community raises serious questions as to the adequacy of discussions as to possible forms of management, including expertise in the procedure. Language issues and attitudes of clinicians may well influence the information and advice given to patients with achalasia from the South Asian community. In a study from Middlesbrough, 95% of Pakistani patients, who spoke Punjabi or Urdu, were not told of the availability of a translation service (47). In the West Midlands older patients, in particular, had issues with understanding information written in English and, of course, many patients with achalasia are older (48). Lack of literacy amongst Pakistani women with diabetes in South Wales led to poorer glycaemic control, despite a targeted education program (49). The use of family members as intermediates in such cases is fraught with its own problems (50). So then, are South Asian patients receiving sufficient information about the forms of treatment available for achalasia to allow them to make an informed choice? There is no evidence to suggest that this is the case. Rather, it would appear that South Asian patients are being guided towards what clinicians believe to be the best option. In the 21st Century such a paternalistic approach to clinical care is unacceptable.

Although this study relies on Freedom of Information data, reassurance as to the overall validity of the results comes from the 40 treatments and 41 estimated patients in Sandwell and West Birmingham, which closely correspond with the 56 patients diagnosed within this Trust between 2006 and 2015 and reported by Harvey *et al.* (6). However, Harvey *et al.*'s study, which reported the highest incidence of achalasia in the UK at $2/10^5$ population/year, must also be treated with caution. It was based on nationally collected data and reported only 79 South Asian patients with achalasia out of 10,509 incident cases reported by Hospital Episode Statistics. The limitations of nationally collected data on achalasia were previously reported for an earlier 10-year study (3). In England, where 5% of the population are of South Asian origin, over a 10-year period between 300 and 600 patients with achalasia, from this community, should have been identified from Hospital Episode Statistics. This discrepancy lends further support to the concept that South Asian patients with achalasia are simply not being diagnosed and in addition to experiencing different patterns of treatment may also have different patterns of referral and investigation. A further limitation to Freedom of Information data includes the diligence of the Trust Officer, who conducts the search (51). However, any deficiencies in the data collection are likely to apply equally across all ethnic communities, as the data are generated through searches of computer-based registries. Clearly, data generated by such searches will also depend upon the accuracy of the original coding, both as to diagnosis and type of procedure. The use of Freedom of Information requests means that the responses are anonymised and so it is not possible to check accuracy through checking the data against a sample of original clinical records and investigations

Different patterns of care between ethnic communities can have a number of causes. This may include patients' cultural views on the management being offered, opposition by cultural leaders, lack of effective communication by clinical staff or simple discrimination. In the case of achalasia, the reasons for the difference in treatment patterns between South Asian and White British patients is not known but warrants urgent further investigation. The positive link between social deprivation and low frequency of treatments for achalasia in both communities points towards factors other than low income, unemployment, limited education, poor health, and poor housing as being causal and underlines the potential for discrimination playing a significant role.

Freedom of Information requests

Bedfordshire Hospitals NHS Foundation Trust 6334 FOI Request; Bradford Teaching Hospitals NHS Foundation Trust FOI 20049a; East Lancashire Hospitals NHS Trust FOI Request Ref 2020/06/01/Mayberry J; Frimley Health NHS Foundation Trust FOI 0225-20; London North West University Healthcare NHS Trust 2823-20; North West Anglia NHS Foundation Trust FOI 2020-388; Northern Care Alliance NHS Group FOI/10251; Sandwell and West Birmingham NHS Trust F20/0047; The Royal Wolverhampton NHS Trust FOI 7785; University Hospitals Birmingham NHS Foundation Trust FOI 0804 2020/21; University Hospitals of Leicester NHS Trust DP/FOI/44096.

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Footnote

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Ethical Statement: The authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. The study was conducted in accordance with the Declaration of Helsinki (as revised in 2013).

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DOES THE FAILURE TO PROVIDE EQUITABLE ACCESS TO TREATMENT LEAD TO ACTION BY NHS ORGANISATIONS? THE CASE OF BIOLOGICS FOR SOUTH ASIANS WITH INFLAMMATORY BOWEL DISEASE

Affifa Farrukh[*] *John Francis Mayberry*[**]

ABSTRACT

Aims: The purpose of this study was to identify whether NHS Trusts where discrimination in the delivery of care to patients from the South Asian community had been demonstrated had taken any actions to address the issue over the subsequent year.

Methods: Freedom of information requests were sent to three trusts which had provided evidence of disparate provision of biologic therapy to patients with Crohn's disease, their associated Clinical Commissioning Groups and HealthWatch organisations to seek evidence they had remedied the situation. Requests were also sent to the Care Quality Commission, NHS Improvement and the Equality and Human Rights Commission seeking examples where they had responded to inequitable delivery of care related to ethnicity.

Results: No organisation had any evidence of responses to the situation, many unable to accept its existence.

Conclusion: Legal duties are discussed and the only remedy appears to be through the tort of negligence.

Key Words: Discrimination, Ethnicity, Biologics, Inflammatory Bowel Disease

INTRODUCTION

Crohn's disease and ulcerative colitis are both chronic incurable inflammatory bowel diseases characterised by diarrhoea and abdominal pain. During the last two decades, these diseases have increased significantly in frequency and spread

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throughout the world.[1] Studies on migrant communities have shown them to be particularly susceptible to aggressive forms of chronic incurable inflammatory bowel disease, especially in the second generation.[2,3] Their cause is unknown and so treatment is directed at control of symptoms rather than cure. Up until the end of the twentieth century, this treatment was limited to a small range of drugs or surgery. The drugs were low cost and surgery could involve significant resections of the bowel and also the formation of a permanent stoma. Both conditions also significantly increase the risk of developing colonic cancer.[4,5] However, during the last decade there have been significant changes in the management of both Crohn's disease and ulcerative colitis with the introduction of monoclonal antibodies. These treatments are expensive, costing between £12,000 and £15,000 per year for the medications alone. Their use is approved by the National Institute for Health and Care Excellence (NICE)[6,7] and this has had significant economic consequences for hospital trusts and Clinical Commissioning Groups (CCGs). The provision of these agents is regulated by a Technology Appraisal Guidance, which means that if they are indicated they *must* be provided to patients. The purpose of Technology Appraisal Guidance is 'to ensure that all NHS patients have equitable access to the most clinically- and cost-effective treatments that are available'.[8]

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[8] NICE, 'Summary of Technology Appraisal Decisions' (*NICE,* 2016) <nice.org.uk/about/what-we-do/our-programmes/nice-guidance/nice-technology-appraisal-guidance/summary-of-decisions> accessed 22 November 2016.

Discrimination in the delivery of care has long been recognised in the United States, but during the last 20 years it has become apparent that this is also true in the United Kingdom.[9] Recent studies have highlighted evidence that South Asian patients have less access to these medications.[10] A study in Leicester demonstrated that South Asian patients with Crohn's disease were four times less likely to receive biologic therapy than their English counterparts.[11] This difference was independent of gender and accounted for age differences between the two communities. A subsequent study looked at the provision of biologic therapy for Crohn's disease in 10 English NHS Trusts, which served areas with the largest ethnic variation.[12] The Freedom of Information (FOI) request revealed that in three trusts, Pennine Acute Hospitals NHS Trust covering Oldham and North Manchester, Barking, Havering & Redbridge University Hospitals NHS Trust and University Hospitals of Leicester NHS Trust, South Asian patients with Crohn's disease were significantly less likely to receive biologic therapy than English patients. One trust, Bradford Teaching Hospitals NHS Foundation Trust, declined to provide information on the basis that it did not collect data on ethnicity. In the remaining trusts there was no evidence of minority populations being underserved. In ulcerative colitis a review of the management of patients over the decade following their initial diagnosis showed that South Asian patients were less likely to be seen by a consultant, less likely to be investigated and more likely to be discharged from hospital based care.[13] There is supportive evidence for such findings from the United States, where discrimination in the delivery of care to ethnic minorities has been long recognised.[14] In the 1990s the American Medical

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[9] NICE (n 8).

[10] A Farrukh and J Mayberry, 'Ethnic Variations in the Provision of Biologic Therapy for Crohn's Disease: A Freedom of Information Study' (2015) 83 Medico-Legal Journal 104; A Farrukh and JF Mayberry, 'Apparent Discrimination in the Provision of Biologic Therapy to Patients with Crohn's Disease According to Ethnicity' (2015) 129 Public Health 460; A Farrukh and JF Mayberry, 'Patients with Ulcerative Colitis from Diverse Populations: The Leicester Experience' (2016) 84 Medico Legal Journal 31; A Farrukh and JF Mayberry, 'Evidences of Differences and Discrimination in the Delivery of Care: Colorectal Screening in Healthy People and in the Care and Surveillance of Patients with Inflammatory Bowel Disease' (2019) 1 Gastrointestinal Disorders 253.

[11] Farrukh and Mayberry (n 12).

[12] Ibid.

[13] Farrukh and Mayberry (n 12).

[14] JF Jackson III, T Dhere, A Repaka, A Shaukat and S Sitaraman, 'Crohn's Disease in an African-American Population' (2008) 336 American Journal of Medical Sciences 389; MH Flasar, T Johnson, MC Roghmann and RK Cross, 'Disparities in the Use of Immunomodulators and Biologics for the Treatment of Inflammatory Bowel Disease: A

Association recognised that 'subconscious bias' may be a factor for such clinical practice.[15] In the United States, Geiger has attributed such differences in care to either 'conscious bias or, more often, unconscious negative stereotyping'[16]. There are no other ready explanations for such differences in the care of patients with inflammatory bowel disease in the United Kingdom. The diseases occur with equal severity in patients of South Asian and English origin, and the studies discussed above compensated for differences in age structure between communities, indicating that the differences in standards of care are real.

The three trusts where patients received disparate care were informed of the results through a range of methods including presentations and publications. The purpose of this study was to investigate the practical responses of Pennine Acute Hospitals NHS Trust, Barking, Havering & Redbridge University Hospitals NHS Trust and University Hospitals of Leicester NHS Trust, to these findings one year later. Related organisations concerned with the delivery of care by these trusts were also contacted to assess what action they had taken. These organisations fell into two groups, namely local and national. Local groups included the Clinical Commissioning Groups (CCGs) and the Health and Well-Being Boards, while national organisations contacted were the Care Quality Commission, NHS Improvement and the Equality and Human Rights Commission. CCGs are clinically led statutory NHS bodies responsible for the planning and commissioning of health care services for their local area. Health and Well-Being Boards commission local HealthWatch organisations. They are a statutory service set up by local councils as part of the Health and Social Care Act 2012. HealthWatch describes its role as:

> … the independent national champion for people who use health and social care services. We're here to make sure that those running services, and the government, put people at the heart of care.[17]

Retrospective Cohort Study' (2008) 14 Inflammatory Bowel Disease 13; OM Damas, DA Jahann, R Reznik, JL McCauley, L Tamariz, AR Deshpande, MT Abreu and DA Sussman, 'Phenotypic Manifestations of Inflammatory Bowel Disease Differ between Hispanics and Non-Hispanic Whites: Results of a Large Cohort Study' (2013) 108 American Journal of Gastroenterology 231.

[15] Council on Ethical and Judicial Affairs American Medical Association, 'Black-White Disparities in Health Care' (1990) 263 Journal of the American Medical Association 2344.

[16] HJ Geiger, 'Racial and Ethnic Disparities in Diagnosis and Treatment: A Review of the Evidence and Consideration of Causes' (2003) in BD Smedley, AY Stith and AR Nelson (eds), *Unequal Treatment Confronting Racial and Ethnic Disparities in Healthcare* (The National Academies Press Washington 2003).

[17] HealthWatch (2019) <healthwatch.co.uk/what-we-do> accessed 13 May/2019.

Each trust is linked with several CCGs and HealthWatch groups, representing different areas which they serve.

The method adopted in this study was to approach each of the three trusts where there was evidence of underserving members of the ethnic minority community who had inflammatory bowel disease. In addition those bodies who have a statutory duty to monitor their delivery of service were also approached. On a local basis this was the CCGs and HealthWatch organisations and nationally CQC, NHS Improvement and EHRC. The technique chosen was to submit a Freedom of Information (FOI) request, as this allowed follow-up questions, when answers lacked clarity. Some authors have expressed the hope that greater transparency in health care will lead to improved services and that FOIs could be one engine for such a change.[18] However, the effectiveness of FOI ultimately depends upon the attitude and commitment with which it is approached by government agencies and their staff as well as public insistence that the statute is implemented in a way which fulfils its purpose.[19]

STUDY

In this study FOI requests were sent to:

1. The three NHS Trusts which had treated fewer South Asian patients than expected, namely Pennine Acute Hospitals NHS Trust, Barking, Havering & Redbridge University Hospitals NHS Trust and University Hospitals of Leicester NHS Trust
2. The Clinical Commissioning Groups (CCGs) and HealthWatch groups commissioned by Health and Wellbeing Boards associated with these three Trusts
3. Care Quality Commission (CQC)
4. NHS Improvement (formerly Monitor)
5. Equality and Human Rights Commission (EHRCC)

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[18] AJ Fowler, RA Agha RA, CF Camm and P Littlejohns, 'The UK Freedom of Information Act (2000) in Healthcare Research: A Systematic Review' (2013) BMJ Open <10.1136/bmjopen-2013-002967> accessed 6 August 2019.

[19] M Berger, 'The Freedom of Information Act: Implications for Public Health Policy and Practice' (2011) 126 Public Health Reports 428.

DOES THE FAILURE TO PROVIDE EQUITABLE ACCESS TO TREATMENT LEAD TO ACTION BY NHS ORGANISATIONS?

NHS Trusts, CCGs and HealthWatch groups were asked to respond to two questions related to the information and published work on disparate care. They were:

1. What actions have the Trust/CCG//HealthWatch taken to ensure equitable access by the South Asian community and other minority groups to treatment with biologics for inflammatory bowel disease?
2. What monitoring systems does the Trust/CCG/HealthWatch have in place to ensure equitable access to treatment with biologics by patients from the South Asian community and other minority groups?

Groups which failed to reply were sent a further request. Where answers were unclear or ambiguous explanations were sought.

The CQC, NHS Improvement and the EHRC were asked:

> 'Can you provide a list of the interventions that the CQC/Monitor or NHS Improvement/EHRC have made when there has been evidence of discrimination in the delivery of care to patients in the NHS based on ethnicity?'

Again where answers were unclear or appeared evasive respondents were asked to expand or clarify their response.

Responses were reviewed for common themes using content analysis.[20] This technique has previously been used in data drawn from multiple sources, including relatively short extracts.[21]

Responses were received from the three NHS Trusts, six CCGs but only one HealthWatch. Those 10 organisations which replied provided answers to all of the questions posed to them. Many of the responses from different organisations across the country were carbon copies of each other, raising the possibility that Freedom of Information requests are responded to with standard answers and hence the need to seek clarification in some cases. The common themes identified from responses were:

1. There is no discrimination in the delivery of care and we deliver clinically appropriate treatment to all patients. This theme was present in responses from all 10 organisations.

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[20] GW Ryan and HR Bernard, 'Techniques to Identify Themes' (2003) 15 Field Methods 85; K Krippendorff, *Content Analysis: An Introduction to Its Methodology* (2nd edn, 2004 Sage).

[21] JF Mayberry, 'An Analysis of Blogs from Medical Students on "English Parallel" Courses in Central and Eastern Europe' (2013) 81 Medico Legal Journal 171.

2. There is no mechanism for routine monitoring whether there is any discrimination in the delivery of care. The data we collect on treatment and ethnicity is too large to allow any analysis. This theme was seen in responses from all NHS Trusts and CCGs
3. The organisation depends upon complaints about discrimination to initiate action and it has not received any. This theme was identified in the response from the HealthWatch organisation.

Examples of responses to Question 1 included:

> 'We can confirm that all our patients are treated without discrimination'.
>
> 'It would be both difficult and unlikely for there not to be equitable access to biologic therapy'.
>
> 'The Trust only starts patients on biologics according to strict clinical criteria'.

No trust had responded to the published findings based on evidence they had supplied through earlier Freedom of Information requests.

Answers to Question 2 included:

> 'It is not considered that there is an access issue within *name of organisation*'.

CCGs stated they were unable to access relevant data. However, if they became aware that:

> access is especially focussed on or restricted amongst particular ethnic groups, then the CCGs would take this issue very seriously and issue a Contract Performance Notice.

The need to monitor equality of access to care is a specific requirement of contracts between CCGs and Trusts and is an obligation on both organisations. The second question addressed this requirement. None of the respondents had any monitoring system in place. Indeed, most organisations tacitly recognised that monitoring equality in delivery of care did not occur. HealthWatch Oldham replied that it had:

> a number of systems in place for monitoring Oldham residents' access to and experience of health and social care services. These include a broad survey of patient experiences as well as using information from NHS Choices, Patient Opinion and the Care Quality Commission.

The common themes reported by CQC and NHS Improvement included:

1. The information cannot be readily accessed from our data collection.
2. It is not within our Terms of Reference; some other body is responsible.

The CQC reported that it would not issue a warning notice for the scenario described in the question as such notices are only used for systemic failures. It went on to state that enforcement actions were on the basis of contravention of Regulations 9, 10 and 17 of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2014. To determine whether breaches of these regulations related to disparity in delivery of care based on ethnicity each action would need to be manually reviewed and the CQC was unwilling to conduct such an exercise. Regulation 9 states:

1. The care and treatment of service users must—
   a. be appropriate,
   b. meet their needs; and
   c. reflect their preferences.
2. Without limiting paragraph (1), the things which a registered person must do to comply with that paragraph include—
   a. carrying out, collaboratively with the relevant person, an assessment of the needs and preferences for care and treatment of the service user;
   b. designing care or treatment with a view to achieving service users' preferences and ensuring their needs are met.

and Regulation 17:

2(e) seek and act on feedback from relevant persons and other persons on the services provided in the carrying on of the regulated activity, for the purposes of continually evaluating and improving such services.

Clearly the underserving of ethnic minorities by Trusts falls within these categories and it is of concern that the CQC did not consider that this represented a systems failure and falls clearly within the grounds for issuing a warning notice. The failure of the CQC to deal with underperformance in a trust has previously been identified in a report by Grant Thornton on University Hospital of Morecombe Bay where it concluded that there had, on the balance of probabilities, been 'an attempt to cover-up matters concerning CQC's regulation of UHMB'.[22]

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[22] Grant Thornton, 'The Care Quality Commission re: Project Ambrose dated 14 June

NHS Improvement's response was that it held *some* logs of its work but they:

> do not go into sufficient granularity to specify whether any of those actions were based on any concerns relating to discrimination based on ethnicity. Please note that NHS Improvement does not have a role in monitoring trusts' compliance with equalities legislation.

This is despite the fact that from 2014 it was tasked with issuing NHS Provider Licences to Trusts providing clinical care. Among the conditions for licenses were:

> 4 (a) improving the quality of health care services provided for the purposes of the NHS (…) or the efficiency of their provision, (b) reducing inequalities between persons with respect to their ability to access those services, and (c) reducing inequalities between persons with respect to the outcomes achieved for them by the provision of those services.[23]

The EHRC considered such issues did fall within its Terms of Reference but reported that:

> Following a search of the Commission's Section 30 intervention records, we have determined that we hold no information relevant to your request.

DISCUSSION

Trusts and their associated bodies are unwilling to accept that there is discrimination in the delivery of care, despite the fact that this has been shown through independent analysis of their own data. Although they have collected these data they consider them too large to allow any analysis and have no structures in place to monitor whether they are delivering an equitable service. Rather they depend upon external complaints by patients about discrimination being made to them, and they deny having received any. In addition, there is no evidence that any NHS Trust or CCG where there was disparate care in delivery of biologics has taken any action to remedy the situation.

2013' <cqc.org.uk/sites/default/files/media/documents/grant_thornton_uk_llp_morecambe_bay.pdf> accessed 13 May 2019.

[23] Monitor, 'The New NHS Provider Licence' (2013) <gov.uk/government/uploads/system/uploads/attachment_data/file/285008/ToPublishLicenceDoc14February.pdf> accessed 1 December 2016.

There Is No Discrimination in the Delivery of Care

Despite the responses from the three NHS trusts and their associated CCGs problems with the equitable delivery of care in the secondary sector are widespread. The situation demonstrated for South Asian patients with inflammatory bowel disease is not unusual. Other examples include Black African women with breast cancer being less likely to have surgery and more likely to be simply offered chemotherapy, while Pakistani women were less likely to be offered radiotherapy or hormone treatment than White women.[24] In the twenty-first century ethnic minority patients on the renal transplant register are still less likely to receive a donor organ than White patients.[25] In the field of mental health Black service users tend to be given injectable depot treatments rather than offered tablets or cognitive behavioural therapy.[26] Further examples include a qualitative study of registered nurses working in hospitals in Leeds which identified racism affecting their care of Pakistani patients.[27] Earlier a group of South Asian inpatients had described how they felt that they needed to fit into what they described as an ‘English place’.[28] In another study from Middlesborough, only 5% of Pakistani patients were told of the availability of professional translators to help with consultations.[29]

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[24] RH Jack, EA Davies and H Møller, ‘Breast Cancer Incidence, Stage, Treatment and Survival in Ethnic Groups in South East England’ (2009) 100 British Journal of Cancer 545.

[25] U Udavaraj, R Pruthi, A Casula and P Roderick, ‘UK Renal Registry 16th Annual Report: Chapter 6 Demographics and Outcomes of Patients from Different Ethnic Groups on Renal Replacement Therapy in the UK’ (2013) 125 Nephron Clinical Practice 111.

[26] J Das-Munshi, D Bhugra and MJ Crawford, ‘Ethnic Minority Inequalities in Access to Treatments for Schizophrenia and Schizoaffective Disorders: Findings from a Nationally Representative Cross-Sectional Study’ (2018) 16 BMC Medicine 55.

[27] JD Cortis, ‘Meeting the Needs of Minority Ethnic Patients’ (2004) 48 Journal of Advanced Nursing 51.

[28] V Vydelingum, ‘South Asian Patients’ Lived Experience of Acute Care in an English Hospital: A Phenomenological Study’ (2000) 32 Journal of Advanced Nursing 100.

[29] R Madhok, A Hameed and R Bhopal, ‘Satisfaction with Health Services among the Pakistani Population in Middlesborough, England’ (1998) 20 Journal of Public Health Medicine 295.

There Is No Mechanism for Routine Monitoring for Discrimination in the Delivery of Care

The Equality Impact Analysis for the NHS for 2016 and for 2017–2018 states that:

> The main types of data and information that evidence inequalities relate to:
>
> - patient access to services, experience and health outcomes.[30,31,32]

Although Trusts are contracted to collect these data they have wide latitude in how this is done but are expected to seek out additional sources of information related to equality of care. Such sources should include published work as well as direct presentations. The guidance that is available on commissioning to reduce inequalities notes that local need is an essential factor to be aware of.[33] However, failure to collect and monitor information on patient ethnicity is widespread. In the Race Equality Service Review only 9 of 24 trusts collected such data. However, only 3 of the 15 who failed to collect the data admitted to doing so.[34] Denial, as in this study on the underserving of South Asian patients, is the standard response to many requests to NHS organisations for information about ethnicity. Indeed a recent study of three Primary Care Trusts in the North of England found that:

> Rather than being embedded within processes of understanding and responding to the health care needs of the local population, ethnic (and other) equalities work was generally constructed as a matter of legal compliance or, as one respondent explained, *a nicety, not a necessity.*[35]

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[30] NHS, 'A refreshed Equality Delivery System for the NHS EDS2 Making Sure That Everyone Counts' (2013) <england.nhs.uk/wp-content/uploads/2013/11/eds-nov131.pdf> accessed 14 May 2019.

[31] NHS England, 'NHS Standard Contracts 2016/17 Equality Impact Analysis' (2016) <england.nhs.uk/wp-content/uploads/2016/03/nhs-std-con-eia.pdf> accessed 14 May 2019.

[32] NHS England, 'NHS Standard Contracts 2017/18 and 2018/19 Equality Impact Analysis' (2016) <england.nhs.uk/wp-content/uploads/2016/12/nhs-std-contract-eia-1718.pdf > accessed 29 January 2017.

[33] Dr Foster Intelligence, *The Intelligent Board 2009: Commissioning to Reduce Inequalities* (Dr Foster Intelligence 2009).

[34] V Lyfar-Cisse, *Race Equality Service Review* (South East Coast BME Network 2008).

[35] S Salway, G Mir D Turner, GT Ellison, L Carter and K Gerrish, 'Obstacles to "Race

The Organisation Depends upon Complaints about Discrimination to Initiate Action

In 2015 the Health Select Committee has described the NHS complaints system in the following terms:

> ….Too many complaints are mishandled with people encountering poor communication or, at worst, a defensive and complicated system which results in a complete breakdown in trust and a failure to improve patient safety.[36]

The problem which this study has identified is that apparently none of the trusts have received any complaints indicating that their treatment policies were discriminatory. The complicated nature of the complaints system makes this not surprising. Indeed even the EHRC has had limited involvement with health care and unequal treatment related to protected characteristics. One of the few examples that has been reported was the formal agreement it made with NHS Tayside.[37] Its purpose was to ensure that all deaf patients would have their communication needs met.

GENERAL COMMENTS

One of the roles of NICE is to ensure that effective medications are available to patients and the specific purpose of its Technology Appraisal Guidance is:

> …….to reduce variations in practice across the country….[38]

These powers are set out in Regulation 7 of Statutory Instrument 2013 No. 259 which states:

> 7 ((6) A relevant health body *must comply with a technology appraisal recommendation.*

Equality" in the English National Health Service: Insights from the Healthcare Commissioning Arena' (2016) 152 Social Science & Medicine 102.

[36] Health Select Committee, *Complaints and Raising Concerns* (HC 2014–2015, 350) para 3.

[37] Equality and Human Rights Commission, 'Section 23 Agreement between the Equality and Human Rights Commission and Tayside Health Board This Agreement dated 7 October 2014' <nhstaysidecdn.scot.nhs.uk> accessed 11 April 2017.

[38] NICE, 'Charter' (2013) <nice.org.uk/Media/Default/About/Who-we-are/NICE_Charter.pdf> accessed 22 November 2016.

Within its Quality Standard for Inflammatory Bowel Disease NICE also recognised:

> Commissioners and providers should aim to achieve the quality standard in their local context, in light of their duties to have due regard to the need to eliminate unlawful discrimination.[39]

Monitor and CQC are charged with supervising the overall functioning of hospitals, but their inspections do not drill down into adherence to individual Guidance. However, in an obiter dicta in *Rose v Thanet Clinical Commissioning Group,* Mr Justice Jay said:

> ……The extent of the public law obligation is to have regard to the relevant NICE guideline and to provide clear reasons for any general policy that does not follow it…[40]

The NHS Litigation Authority has recognised the need for organisations to have mechanisms for monitoring implementation of NICE Guidelines.[41] Where a Trust fails to do so, it is conceivable that a judicial review could require that organisation to reformulate its policies. Medical Directors were given responsibility for implementation and so failures might raise questions concerning their fitness to practice and lead to referral to the GMC. However, the question remains as to who would seek such a review or make such a referral.

The Public Sector Equality Duty identified in the Equality Act is the basis for the statement in the NHS Constitution that:

> Legal duties require NHS England and each clinical commissioning group to have regard to the need to reduce inequalities in access to health services and the outcomes achieved for patients.[42]

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[39] NICE, 'Inflammatory Bowel Disease' (2015) <nice.org.uk/guidance/qs81> accessed 14 May 2019.

[40] [2014] EWHC 1182 (Admin).

[41] NHS Litigation Authority, 'An Organisation-Wide Document for the Dissemination, Implementation and Monitoring of NICE Guidance' (2012) <nhsla.com/.../Document%20for%20the%20Dissemination%20Implementation%> accessed 1 December 2016.

[42] Department of Health, 'Guidance: The NHS Constitution for England' (2015) <gov.uk/government/publications/the-nhs-constitution-for-england/the-nhs-constitution-for-england> accessed 14 May 2019.

Sections 212 and 213 of the Act make it clear that *omission* carries the same legal consequences as a requirement to perform a service. In 2013 Monitor was tasked with issuing Provider Licences to Trusts and among the conditions is:

> ... 4 (b) reducing inequalities between persons with respect to their ability to access those services....[43]

Monitor has been subsumed within NHS Improvement, but the organisation's response was:

> … Please note that NHS Improvement does not have a role in monitoring trusts' compliance with equalities legislation.

Which COMMENT suggests it is unaware of its responsibilities under 4(b). Unfortunately, section 71 of the Health and Social Care Act (2012) provides no remedy to the ordinary citizen if Monitor fails in performance of its functions.

CQC considers its objectives are to:

> … help to focus providers and commissioners on the importance of their responsibilities towards equality, diversity and human rights, and to improvement[44]

and ensure:

> … an organisation provides services proportionately to different groups and their needs[45]

So it is disappointing that CQC is unable to readily identify any occasion when it has issued enforcement actions concerned with inequality in delivery of care related to ethnic diversity.

The Health and Social Care Act 2012 created Health and Social Welfare Boards to ensure local needs were met. However, such Boards lack formal powers

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[43] Monitor, 'The New NHS Provider Licence' (2013) <gov.uk/government/uploads/system/uploads/attachment_data/file/285008/ToPublishLicenceDoc14February.pdf> accessed 14 May 2019.

[44] Care Quality Commission, 'Equality and Human Rights Impact Assessment' (*EHRIA*, 2010) <cqc.org.uk/sites/default/files/documents/20100630_31_assessments_of_quality_eia_pub_version.pdf> accessed 14 May 2019.

[45] Ibid.

to instruct CCGs or NHS Trusts and by building good relationships hope to influence decisions by these bodies. Their present role appears little more than that of a talking shop.

The question as to why Trusts and related organisations have failed to respond to the evidence of discrimination in the delivery of care is critical to any future actions to improve the situation. Interestingly in an earlier study of English Primary Care Trusts Salway et al. found that

> ……consideration of ethnicity was often treated as a matter of legal compliance rather than ntegral to understanding and meeting healthcare needs. Many managers and teams did not consider tackling ethnic healthcare inequities to be part-and-parcel of their job, lacked confidence and skills to do so, and questioned the legitimacy of such work…..[46]

The questioning of the legitimacy of such findings is common to this report. None of the respondent organisations identified any attempt by management to address these issues, often on the basis that they simply could not be true. Dilworth-Anderson et al.[47] (48) have suggested that in the US cultural interpretation of disease plays a central role with disparities in care being attributed to perceived rather than real differences and so legitimising a 'Do nothing' approach, because nothing needed to be done.

CONCLUSION

So where lies hope for a disadvantaged group of patients? Sadly the most likely route for individuals is through the tort of negligence. Clearly there will have been a breach of duty and but for that breach patients would have experienced a better quality of life through use of biologics and there is emerging data that their disease may have followed a different course. Any current hope that there will be management-driven changes or interventions by regulatory bodies seems forlorn.

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[46] Salway et al (n 37).

[47] P Dilworth-Anderson, G Pierre and TS Hilliard, 'Social Justice, Health Disparities, and Culture in the Care of the Elderly' (2012) 152 Journal of Law & Medical Ethics 26.

Denning Law Journal 2020 Vol 32 p 51-86

WHAT ARE THE LEGAL MECHANISMS FOR SEEKING SOLUTIONS TO DISPARITIES IN THE DELIVERY OF CARE IN THE NHS AND WHERE DOES LIABILITY LIE?

Affifa Farrukh[*]

> *This fundamental principle: that we are all citizens, and equal citizens, of one State:*[1]
>
> Muhammad Ali Jinnah

ABSTRACT

This review deals with the potential role of Commissions and Inquiries into delivering a just service to patients from ethnic minorities. It takes as an example the experience of people with inflammatory bowel disease and the National Health Service in the United Kingdom. Although there are many legal safeguards, the avenues open to groups of patients who experience discrimination, are limited and generally ineffective. Government inspired responses such as Commissions and Inquiries are inadequate and not fit for purpose.

Key words: Discrimination, Healthcare, NHS, Commissions, Inquiries, Judicial Review

INTRODUCTION

Ethnic discrimination in delivery of health care is a worldwide problem. Well-known examples include the notorious Tuskegee experiment where the US Public Health Service withheld appropriate treatment for syphilis from more than 600 African American share croppers between 1932 and 1972.[2] However, the issue was and is much more widespread than the Deep South. In 1988 Kjellstrand demonstrated that non-White patients were half as likely to receive a kidney

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[1] Muhammad Ali Jinnah's first Presidential Address to the Constituent Assembly of Pakistan (11 August 1947) para 7.

[2] JH Jones, *Bad Blood: The Tuskagee Syphilis Experiment* (The Free Press 1992) 1.

transplant across the USA.[3] Similarly, Black patients were twice as likely to go untreated for bladder cancer.[4] By the end of the 20th century it was well recognised within the USA that Black patients were less likely than White patients with a comparable disease burden to undergo cardiac revascularisation, leading to lower survival rates.[5] In 1998 Bhopal from Newcastle summarised the effect of discrimination on health care in the USA and drew attention to similar issues in the UK.[6]

EXAMPLES OF DISCRIMINATION IN THE DELIVERY OF CARE IN THE UK

In 1998 a study from Leicester had shown that South Asian patients admitted into coronary care units received poorer care than their European counterparts.[7] Such differences in the nature of the support and treatment offered to patients from ethnic minorities in the UK continue to be reported. Black women with breast cancer were less likely to have surgery and more likely to be simply offered chemotherapy, whilst Pakistani women were less likely to be offered radiotherapy or hormone treatment than White women.[8] In the UK in the 21st-century ethnic minority patients on the renal transplant register are still less likely to receive a donor organ than White patients.[9] In the field of mental health, Black service users tend to be given injectable depot treatments rather than offered tablets or cognitive

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[3] CM Kjellstrand, ‘Age, sex and race inequality in renal transplantation’ (1988) 148 Archives of Internal Medicine 1305.

[4] WJ Mayer and WP McWhorter, ‘Black/White differences in non-treatment of bladder cancer patients and implications for survival’ (1989) 79 American Journal of Public Health 772.

[5] ED Peterson and others, ‘Racial variation in the use of coronary – revascularization procedures. Are the differences real? Do they matter?’ (1997) 336 New England Journal of Medicine 480.

[6] R Bhopal, ‘Spectre of race and racism in health and health care: lessons from history and the United States’ (1988) 316 British Medical Journal 1970.

[7] JT Lear and others, ‘Myocardial infarction and thrombolysis: a comparison of the Indian and European populations on a coronary care unit’ (1994) 28 Journal of the Royal College of Physicians (London) 143.

[8] RH Jack, EA Davies and H Møller, ‘Breast cancer incidence, stage, treatment and survival in ethnic groups in South East England’ (2009) 100 British Journal of Cancer 545.

[9] U Udavaraj and others, ‘UK Renal Registry 16th annual report: chapter 6 demographics and outcomes of patients from different ethnic groups on renal replacement therapy in the UK’ (2013) 125 Nephron Clinical Practice 111.

behavioural therapy.[10] Although such differences are not policy driven it seems unlikely that they are due to overt racism. In a study of nine NHS trusts with significant South Asian populations only three were significantly less likely to provide expensive biologic therapy for South Asian patients with Crohn's disease.[11] In one of these trusts, a separate study found that South Asian patients with ulcerative colitis experienced sub-standard care over a 10-year period when compared to White British patients.[12] This included being seen less often by consultants, less frequent investigations and being discharged more frequently. There was no evidence that they had milder disease as they needed surgery as often as White British patients.

National Health Service (NHS) workers have shown patients various forms of discrimination. For example, a qualitative study of 30 registered nurses working in hospitals in Leeds identified racism affecting their practice in their care of Pakistani patients.[13] Earlier a small group of South Asian inpatients had described how they felt that they needed to fit into what they described as an 'English place'.[14] In Middlesbrough, only 5 per cent of Pakistani patients were told of the availability of professional translators to help with consultations.[15] Problems with effective communication between district nurses and South Asian patients meant compliance with treatment regimes was not fully understood and assessments of patients' ongoing needs were inaccurate.[16] NHS England recognised the importance of this issue in a policy statement directed at ensuring that a high quality interpreting and

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[10] J Das-Munshi, D Bhugra and MJ Crawford, 'Ethnic minority inequalities in access to treatments for schizophrenia and schizoaffective disorders: findings from a nationally representative cross-sectional study' (2018) 16 BMC Medicine 55.

[11] A Farrukh and JF Mayberry, 'Ethnic variations in the provision of biologic therapy for Crohn's disease: a Freedom of Information study' (2015) 83 MedicoLegal Journal 104.

[12] A Farrukh and J Mayberry, 'Patients with ulcerative colitis from diverse populations: the Leicester experience' (2016) 84 MedicoLegal Journal 31.

[13] JD Cortis, 'Meeting the needs of minority ethnic patients' (2004) 48 Journal of Advanced Nursing 51.

[14] V Vydelingum, 'South Asian patients' lived experience of acute care in an English hospital: a phenomenological study' (2000) 32 Journal of Advanced Nursing 100.

[15] R Madhok, A Hameed and R Bhopal, 'Satisfaction with health services among the Pakistani population in Middlesborough, England' (1998) 20 Journal of Public Health Medicine 295.

[16] K Gerrish, 'The nature and effect of communication difficulties arising from interactions between district nurses and South Asian patients and their carers' (2001) 33 Journal of Advanced Nursing 566.

translation service was available.[17] Unfortunately the Care Quality Commission has shown this is often not readily available with hospitals making use of limited telephone translation services and non-professional staff.[18]

THE NATURE OF THE EVIDENCE AND POTENTIAL RESPONSES

Over the last 20 years a substantial body of evidence has demonstrated that there is significant discrimination in the way health care is accessed and delivered by the NHS. This discrimination has an ethnic basis and can have a direct impact on morbidity and mortality. The studies have been conducted on cohorts of patients and used epidemiological techniques. Individual cases have not been reported in the medical literature and when, and if, litigation has been contemplated it is likely such cases were settled prior to any trial on a no admission of liability basis and have included clauses about confidentiality. However, there is also evidence that discrimination based on ethnicity is not universal and so provides hope that appropriate interventions, including legal ones, might change such behaviour patterns. Indeed Sir William MacPherson summarised the situation by suggesting:

> It is incumbent on every institution to examine their policies and the outcomes of their policies and practices to guard against disadvantaging any section of our communities… There must be an unequivocal acceptance of institutional racism and its nature before it can be addressed.[19]

This review will investigate the potential role of judicial processes in dealing with discrimination in the delivery of care, as education, non-legal interventions and published research alone have failed. The routes to obtaining a more just delivery of care will be considered and patients with inflammatory bowel disease will act as a model. However, the observations will apply across the board and in

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[17] NHS England, 'Principles for high quality interpreting and translation services (Version 1.19)' <www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2015/03/it_principles.pdf> accessed 4 November 2018.

[18] Care Quality Commission, *University Hospitals of Leicester NHS Trust Quality Report* (2014) <www.cqc.org.uk/sites/default/files/new_reports/AAAA0708.pdf> accessed 4 November 2018.

[19] Home Office, *The Stephen Lawrence Inquiry* (Cm4262–1, 1999) 109 </assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/277111/4262.pdf> accessed 7 May 2020.

some areas all groups will be considered together. The major approaches that will be discussed will be Royal Commissions, Inquiries and Judicial Review.

POTENTIAL LEGAL APPROACHES TO THE ISSUE OF DISCRIMINATION IN DELIVERY OF CARE TO BLACK AND ETHNIC MINORITIES

The information available on discrimination in delivery of care to Black and Ethnic Minorities (BEM) is almost exclusively based on qualitative social research and quantitative epidemiological studies. There is no evidence publicly available of individuals who have sued in tort or contract where breach of duty has been linked to racism in the UK. To some degree this contrasts with the situation in the USA where at a press conference called by the Medical Committee for Human Rights, Dr Martin Luther King said: "Of all the forms of inequality, injustice in health is the most shocking and the most inhuman because it often results in physical death."[20] He went on to accuse the American Medical Association of a "conspiracy of inaction" with a call for court action against doctors to enforce the Civil Rights Act.[21]

ETHNIC DISCRIMINATION IN HEALTH IN UK

In 1987 the Commission for Racial Equality found that 40 per cent of white doctors and 50 per cent of BEM doctors working across England believed there was discrimination in the NHS which affected people's health.[22] Subsequently Ahmad et al. reported that general practitioners held negative attitudes about Asian patients, considering them to require more time and be less compliant.[23]

The issues in question are what approaches might be taken to change the situation for the BEM population as a whole and how should individuals who have experienced poor care and suffered injury – the classic breach of duty and causation scenario – be best advised.

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[20] Associated Press, 'King berates medical care given negroes' *Oshkosh Daily Northwestern* (Oshkosh, Wisconsin, 26 March 1966) <www.hcdi.com/2018/01/12/dr-martin-luther-king-on-health-care-injustice> accessed 7 May 2020.

[21] J Hoberman, *Black and Blue. The Origins and Consequences of Medical Racism* (University of California Press 2012) 27.

[22] L Kushnick, 'Racism, the National Health Service, and the health of Black people' (1988) 18 International Journal of Health Service 457.

[23] WIU Ahmad, M Baker and E Kernohan, 'General practitioners perceptions of Asian and non-Asian patients' (1991) 8 Family Practice – An International Journal 52.

HOW TO DEAL WITH POOR CARE FOR THE BEM POPULATION

The issue of poor care due to ethnicity is unacceptable nationally and so should be dealt with at that level. Indeed, as most data relate to qualitative or large population studies, such an approach may be the only effective way in which any progress can be made.

The three main routes which might be followed are: a Royal Commission, a Public Inquiry or a Judicial Review.

1. Royal Commissions

Royal Commissions are set up by government in the name of the Crown to advise in a non-partisan way on controversial issues of national importance. They are usually concerned with broad policy issues and generally take between two and four years to deliver a report. They have dealt with health issues, but their use has declined over the last 30 years. An example of such a commission was in the long-term care of the elderly.[24] However, its effectiveness was limited by a dissentient note of two members who considered the proposals financially unrealistic and its main recommendation was rejected by the government.[25]

2. Public Inquiries

During the last 20 years Public Inquiries have become significant tools for investigation of accountability. In healthcare this has included the BSE and the Shipman Inquiries.[26] Beer has argued their purpose is to identify precisely what happened,

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[24] S Sutherland, *Royal Commission on Long Term Care. With Respect to Old Age* (Stationery Office 1999) 1.

[25] R Stout, 'Response to Royal Commission on long term care' (2000) British Medical Journal 315 <bmj.com/rapid-response/2011/10/28/response-royal-commission-long-term-care> accessed 7 May 2020.

[26] L Phillips, *The BSE Inquiry* (The Stationery Office 2000) 1 <webarchive.nationalarchives.gov.uk/20060802142310/http://www.bseinquiry.gov.uk> accessed 7 May 2020; J Smith *The Shipman Inquiry* (The Stationery Office 2005) 1 <https://www.pslhub.org/learn/investigations-risk-management-and-legal-issues/investigations-and-complaints/investigation-reports/other-reports-and-enquiries/the-shipman-inquiry-2002-2005-r867/> accessed 7 May 2020.

decide why it happened and who was to blame and also to identify what can be done to prevent it happening again.[27]

All statutory inquiries are now regulated by the Inquiries Act 2005. In s 2(1) it limits the remit of an Inquiry so it may not "rule on, and has no power to determine, any person's civil or criminal liability". However, in s 2(2) it states "an inquiry panel is not to be inhibited in the discharge of its functions by any likelihood of liability being inferred from facts that it determines or recommendations that it makes".

The public have greatest trust in Inquiries chaired by doctors and nurses.[28] However, in any Inquiry into why patients from ethnic minorities receive poorer quality care, members of these two professional groups would have an obvious conflict of interest. An example where a Public Inquiry into health service issues was chaired by someone without a healthcare background was that led by Professor Kennedy into paediatric cardiac surgery at Bristol Royal Infirmary.[29] Its probing nature had a significant impact on health care in the UK. It identified a "club culture" amongst surgeons with a lack of insight into their clinical failings.[30] This situation is all too reminiscent of the care experienced by BEM patients. As a direct result of the inquiry some 16 years later NHS England set as its objectives:

> Securing the best outcomes for all …..
> Tackling variation ….
> Improving patient experience.[31]

Unfortunately, this standard was only for paediatric cardiac surgery services.

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[27] J Beer, 'Introduction' in J Beer, J Dingemans and R Lissack, *Public Inquiries* (OUP 2011) 1.

[28] Institute for Government, 'General trust in the professions of individuals who have chaired public inquiries since 1990' (2017) <instituteforgovernment.org.uk/charts/general-trust-professions-individuals-who-have-chaired-public-inquiries-1990> accessed 7 May 2020.

[29] Department of Health, *Learning from Bristol: the report of the public inquiry into children's heart surgery at the Bristol Royal Infirmary 1984–1995* (Cm 5207 – 1, 2001) 1.

[30] C Dyer, 'Bristol Inquiry condemns hospital's "club culture"' (2001) 323 British Medical Journal 181.

[31] NHS England, 'Action to implement recommended standards nationally to be announced next week' (2016) <england.nhs.uk/2016/06/childrens-heart-surgery-standards/> accessed 7 May 2020.

3. Judicial Review

Lord Donaldson MR in *R v Lancashire County Council ex p. Huddleston* described the role of judicial review in the 21st century as "a new relationship between the courts and those who derive their authority from public law, one of partnership based on a common aim, namely the maintenance of the highest standards of public administration".[32] There is a contractual duty of candour imposed on all providers of services to NHS patients in the UK to give them all necessary support and relevant information in the event of a reportable patient safety incident, which could have or did result in moderate or severe harm or death. The fact that the duty exists where harm "could" have been caused would suggest that once clinicians become aware their unit is delivering sub-standard care, they are under a professional, and probably legal, obligation to inform BEM patients individually. Such patients would need to be told their care will be comparable to that of an English patient if they go to a different NHS Trust which serves all communities equally. In individual cases, any sub-standard care with adverse consequences would be actionable, under the tort of negligence.

Of course, such racist attitudes should have been dealt with by the Trust's management as it contravenes the first "right" under the NHS Constitution:

> The NHS provides a comprehensive service, available to all irrespective of gender, race, disability, age, sexual orientation, religion, belief, gender reassignment, pregnancy and maternity or marital or civil partnership status. The service is designed to improve, prevent, diagnose and treat both physical and mental health problems with equal regard. It has a duty to each and every individual that it serves and must respect their human rights. *At the same time, it has a wider social duty to promote equality through the services it provides and to pay particular attention to groups or sections of society where improvements in health and life expectancy are not keeping pace with the rest of the population* (Italics added for emphasis).[33]

The abuse experienced by elderly patients at Stafford Hospital led to a Public Inquiry and successful claims against Mid Staffordshire NHS Foundation Trust based on wilful negligence and contravention of Articles 2, 3 and 8 of the Human Rights Act (1998). Nevertheless, it is more likely individuals who have experienced poor care and suffered damage will continue to seek compensation through the

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[32] [1986] 2 All ER 941.

[33] Department of Health, *The NHS Constitution – The NHS belongs to us all* (Williams Lea 2015) 2.

traditional route of medical negligence claims. However, judicial review has a clear role to play in deciding whether a public body has made its decisions in an arbitrary or thoughtless way. The traditional purpose of judicial review has been to examine the legality of decisions made by government or by its agents. A victory by a claimant can have various outcomes, but in relation to discrimination an NHS trust could be required to change its policies so as to eliminate inequitable care.

HOW TO DEAL WITH POOR CARE FOR INDIVIDUALS FROM THE BEM POPULATION

Poor care for patients from the BEM population is both a breach of duty of care and of professional duty. The General Medical Council's (GMC) equivalent of a Core Duty in *Good Medical Practice* at Domain 4 s59 states:

> You must not unfairly discriminate against patients or colleagues by allowing your personal views to affect your professional relationships or the treatment you provide or arrange. You should challenge colleagues if their behaviour does not comply with this guidance.[34]

The guidance clarifies that it includes: "your views about a patient's or colleagues lifestyle, culture or their social or economic status, as well as the characteristics protected by legislation".[35] The GMC enlarges on the consequences of a doctor's personal beliefs and attitudes and states he or she must not: "treat patients unfairly, … deny patients access to appropriate medical treatment or services, …. not cause patients distress".[36] Although this latter guidance largely relates to situations where doctors have a conscientious objection to providing certain procedures, such as termination of pregnancy and male circumcision, it is also directly relevant to work in a Trust which underserves members of the BEM community. Failure to inform patients that a Trust has been underserving the BEM could form grounds for referral to a Fitness to Practice Committee. If the complaint

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[34] General Medical Council, *Good Medical Practice* <gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/good-medical-practice/domain-4---maintaining-trust#paragraph-59> accessed 7 May 2020.

[35] ibid.

[36] General Medical Council, *Personal Beliefs and Medical Practice* 4 <gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/personal-beliefs-and-medical-practice/personal-beliefs-and-medical-practice> accessed 7 May 2020.

is upheld by the Medical Practitioners Tribunal this could lead to either suspension or permanent erasure of that doctor from the medical register.[37]

However, none of these actions will compensate a patient or family members for poor treatment which has caused harm. The most effective route for seeking financial redress in such a situation remains through the tort of negligence. In this case the issue of why a patient received sub-standard treatment is of limited importance, rather it is whether they received such treatment and how it compares with that provided by a competent practitioner.

ROYAL COMMISSION FOR INVESTIGATION OF BEM HEALTHCARE

In 1085 William the Conqueror instituted the first Royal Commission when he sent commissioners throughout the country to collect data which would constitute the Domesday Book. Its purpose was to record property holdings and this concept of investigating and reporting on a specific matter remains the essence of Royal Commissions, although they now lack the enforcement powers which William gave to his commissioners.

In the UK the executive initiates Commissions through powers delegated to it by the Crown. Starr has pointed out that most recent Royal Commissions have been concerned with broad policy rather than specific issues requiring timely actions.[38] As a result there has been only one recent example dealing with health issues. This was the Royal Commission on the National Health Service, which commenced work in 1976 and delivered its report three years later. Its terms of reference were to consider "the best use and management of financial and manpower resources of the National Health Service".[39] What remains unclear is "why, on some occasions, are the recommendations of advisory bodies accepted and implemented with alacrity while at other times they are side-lined, buried or wilfully ignored?"[40] Owens went on further to suggest that "the authority of the

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[37] General Medical Council, *Fitness to Practice Procedures* <whatdotheyknow.com/request/223973/response/564046/attach/html/3/Apok%206512%20response.pdf.html> accessed 7 May 2020.

[38] G Starr, 'Public inquiries in the United Kingdom' in S Prasser and H Tracey (eds), *Royal Commissions & Public Inquiries: Practice & Potential* (Connor Court Publishing Pty Ltd 2014) para 3.01.

[39] A Merrison, *Royal Commission on the National Health Service: Report* (HMSO 1979) 1.

[40] S Owens, 'Experts and the Environment: The UK Royal Commission on Environmental Pollution 1970-2011' (2012) 24 Journal of Environmental Law 1.

advice and its interplay with interests, institutions and power" were important factors, but with time these tended to diminish.

1. Royal Commissions and Health Issues

Despite such apparent restrictions, the Royal Commission on the National Health Service took a wide view of its remit and considered its work must be informed by the notion that the NHS was "a service to patients".[41] Almost 40 years later, observations made in the report continue to be relevant and this emphasises the potential long-term value of Royal Commissions. For example, it took the view that it should: "have some comments on the way NHS priorities are determined. First, we believe it is important that the lay public should be involved in the process".[42]

However, the BEM community were viewed as contributing to the difficulties of the NHS rather than being a group who were underserved. These views were reflected in the following extracts:

> 7.53 Some of these symptoms are due to economic decline and the accompanying poverty and social problems, but others may arise from the high cost of accommodation or the special demands of an aged, *migrant* or homeless population.[43]
>
> 7.61 The special needs of patients who come from ethnic minorities require sensitive handling by the NHS. The evidence we took from their representatives suggests that many NHS workers are not aware of cultural, language, literacy and dietary problems which may affect these groups.[44]

Although the issues of the BEM community only figured in a relatively small way in this report, during recent years they have come more to the fore. The question, however, is whether they would be considered sufficiently broad and of such importance as to warrant a Royal Commission investigating the issue over a period of years and at considerable expense.

The Royal Commission on the NHS was initiated under a Labour government, but its report was published when Margaret Thatcher was Prime Minister and most of its recommendations were not implemented. This underlines the major weakness of Commissions which is that their recommendations lack legal force.

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[41] ibid para 1.1.
[42] ibid para 6.7.
[43] ibid para 7.53.
[44] ibid para 7.61.

However, recently Saatchi (2017) has suggested that there is a growing appetite for the appointment of a Royal Commission to sort out the current problems of the NHS:

> As a constitutional mechanism, a Royal Commission is uniquely placed to draw attention to some of the enormous, long-term challenges that many members of the public, and Westminster, are not fully aware of. A Commission's investigatory powers, and capacity to provide evidenced-based review free from the constraints of the immediate political cycle, allow it to craft solutions that command the support of practitioners and politicians alike. When set up properly, its recommendations carry a unique legitimacy that could be essential to securing a lasting, bipartisan settlement on the NHS.[45]

Within the issues Saatchi considered most pressing was that of underserved BEM communities within the UK. If he is correct that there is a bipartisan wish within Parliament to see a Royal Commission to deal with these issues then it could become a reality.

2. Mechanisms for a Royal Commission

Royal Commissions are created by a formal Order in Council and confirmed with the Great Seal.[46] Subsequently an advertisement is placed by the Privy Council in The Gazette which can: "specify the leader of the commission to be appointed, or an invitation to submit evidence to the inquiry or other matters pertaining to royal commissions".[47] Its membership will generally be selected incrementally and eclectically from amongst experts and lay people.[48] Clearly the composition of any Royal Commission concerned with discrimination in the delivery of health care would be critical and need to represent those whom the NHS is meant to serve.

Royal Commissions lack statutory power to compel witnesses to attend and for documents to be disclosed, but their strength lies in the formality of the

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[45] M Saatchi, *An NHS Royal Commission. From Fighting Fires to Lasting Settlements* (Centre for Policy Studies 2017) 14.

[46] TJ Lockwood, 'A History of Royal Commissions' (1967) 5 Osgoode Hall Law Journal 172.

[47] 'Appointment of Royal Commissions (1112)' <www.thegazette.co.uk/all-notices/content/121> accessed 7 May 2015.

[48] PA Thomas, 'Royal commissions' (1982) 3 Statute Law Review 40.

proceedings and the prestige of being conducted under a royal warrant.[49] Although the median time to produce a report is between two and four years, at least a dozen commissions have done so more rapidly,[50] although time would not be a factor in this case.

3. Public Inquiries and BEM Healthcare

Howe (1999) described the purpose of inquiries as being to provide "a full and fair account of what happened especially in circumstances where the facts are disputed, or the course and causation of events is not clear".[51] This is directly relevant to discrimination in delivery of care to BEM communities which Trusts and individual doctors dispute and its cause is unclear. A more cynical interpretation of their role has been put forward by Habermas who considers their purpose is to re-establish and justify state authority, and thus to maintain 'the requisite level of mass loyalty'[52] In similar vein, Brown believes such "public discourse depoliticizes disaster events, legitimates social institutions, and lessens anxieties by concocting myths that emphasize our omnipotence and capacity to control".[53]

In 2005 the Inquiries Act established statutory inquiries and in 2006 the Inquiry Rules were published. Non-statutory inquiries continue, however, and are still used by a variety of organisations including the NHS. The choice as to which of these two forms an inquiry will take often appears quite arbitrary.

STATUTORY PUBLIC INQUIRIES

The Inquiries Act 2005 enables a Minister to create an inquiry:

> 1 (1) ….. where it appears to him that
>
> (a) particular events have caused, or are capable of causing, public concern

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[49] AW Bradley and KD Ewing, *Constitutional and Administrative Law* (13th edn, Longman 2003) 305; JS Caird, 'Public Inquiries: non-statutory commissions of inquiry' (2016) 02599 House of Commons Library Briefing Paper 20.

[50] P Barlow, 'The lost world of royal commissions' (2013) <instituteforgovernment.org.uk/blog/lost-world-royal-commissions> accessed 7 May 2020.

[51] G Howe, 'The management of public inquiries' (2002) 70 The Political Quarterly 295.

[52] J Habermas, *Legitimation crisis* (Beacon Press 1973) 46.

[53] A Brown, 'Authoritative Sensemaking in a Public Inquiry Report' (2003) 25 Organization Studies 952.

The chairman, its membership and final terms of reference are determined by the minister. He must inform Parliament of his actions, but does not require its permission or approval. Therefore, such Inquiries are under the control of the Executive. Hence their role in investigation of discrimination in the delivery of care by the NHS might be undermined. However, there is some hope. In 2018, an independent public statutory inquiry into the use of infected blood was set up. Its terms of reference are:

> To examine the circumstances in which men, women and children treated by National Health Services in the United Kingdom (collectively, the "NHS") were given infected blood and infected blood products, in particular since 1970.[54]

Clearly the role of the NHS will be investigated, but it must be remembered it has taken almost 50 years to arrive at this point, and this included the non-statutory Archer Inquiry in 2009.[55] This inquiry was funded privately by individuals, the Southern Building Company and the Professional Footballers Association.[56] Its fate is a salutary lesson as it went offline and became difficult to access. As Whyte (2010) has pointed out even a statutory inquiry "is a legally sanctioned forum that has no power of legal sanction".[57]

1. Statutory Inquiries and Health Issues

However, statutory inquiries can limit the information which they publish under s 25 when there is:

> (5) (b) any risk of harm or damage that could be avoided or reduced by withholding any material;
>   (c) any conditions as to confidentiality subject to which a person acquired information that he has given to the inquiry.
> (6) In subsection (5)(b) "harm or damage" includes in particular—
>   (a) death or injury[58]

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[54] <infectedbloodinquiry.org.uk/sites/default/files/Terms-of-Reference-Infected-Blood-Inquiry.pdf> accessed 7 May 2020.

[55] Independent Public Inquiry: Contaminated Blood & Blood Products <archercbbp.com/public> accessed 7 May 2020.

[56] Archer Report 2009 <factor8scandal.uk/archer-report-2009> accessed 7 May 2020.

[57] D Whyte, 'Don't Mention the Motive for War' (2010) 82 Criminal Justice Matters 8.

[58] The Inquiries Act 2005.

All medical information is confidential and many patients would feel that they had suffered further harm on discovering that they had received less appropriate care than other UK citizens.

A further major limitation of statutory inquiries is that: "2 (1) An inquiry panel is not to rule on, and has no power to determine, any person's civil or criminal liability".[59] This has significant implications for recipients of infected blood and would have similar consequences for any inquiry into discrimination in delivery of healthcare.

Under s 19 of the Act restrictions can be imposed by a minister on disclosure or publication of evidence provided to the inquiry as well as limiting public attendance. Public acknowledgement of discrimination in delivery of care might be seen by the Executive as a matter which would not allay public concerns and so lead to suppression of any relevant evidence or its publication. For such reasons, many judges, such as Saville L, would decline to chair inquiries held under the Act.[60] To some degree this may explain the limited number of inquiries held under the Act and the continuing popularity of non-statutory inquiries. In addition, Elliott has drawn attention to the belief that when a judge does chair an inquiry into matters of public concern there will be greater accountability and clearer evidence of independence from the Executive.[61] Clearly, when a minister controls the processes of an inquiry these beliefs would be seriously undermined.

Other statutory inquiries related to health have included the Cdiff Inquiry, the Vale of Leven Inquiry, the Penrose Inquiry on infected blood in Scotland and the Mid Staffordshire NHS Foundation Trust Inquiry.[62] The Cdiff Inquiry was chaired by the Chief Medical Officer for Wales and its three other members were all from medical backgrounds. It was concerned with an outbreak of *Clostridium difficile* induced diarrhoea in hospitals in Northern Ireland and was linked to 31 deaths. The report is no longer readily available. In contrast the Vale of Leven Inquiry which was chaired by a retired judge, MacLean L, is still available. It too concerned the death of 34 patients from *Clostridium difficile* and was set up by the Scottish government in response to public pressure. The same is also true for the Penrose Inquiry into Hepatitis C/HIV infection acquired from infected blood supplies in Scotland, where the chairman was a Scottish Court of Session judge.

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[59] The Inquiries Act 2005.

[60] Beer (n 27) 25.

[61] M Ellliott, 'Should judges lead public inquiries?' (2014) <publiclawforeveryone.com/2014/07/10/should-judges-lead-public-inquiries> accessed 7 May 2020.

[62] G Cowie and M Sandford, 'Statutory Commissions of Inquiry: the Inquiries Act 2005' (2018) SN06410 House of Commons Library Briefing Paper 32.

2. Statutory Inquiries and Public Pressure

In the case of the Vale of Leven Inquiry pressure came from families of those who had died in the *Clostridium difficile* outbreaks, as well as senior members of the medical profession for a public statutory inquiry. However, the turning point was an exchange between Nicola Sturgeon, who was Cabinet Secretary for Health and Wellbeing, whilst standing in for the First Minister, and Iain Gray at First Minister's Question Time:

> The families of those who died want a public inquiry now. Britain's leading epidemiologist wants a public inquiry now. This Parliament voted for a public inquiry in September. Ms Sturgeon has admitted today that there is no reason why that cannot happen. She herself is the only obstacle. How many people need to tell her that she is wrong before she calls a public inquiry?[63]

Although the report was robust in its criticisms, interested parties still accused it of being an example of the NHS investigating itself.[64] Nevertheless, it specifically stated: "Scottish Ministers bear ultimate responsibility for NHS Scotland and even at the level of the Scottish Government the systems were simply not adequate."[65]

3. Statutory Inquiries and Politics

In 2004 Sir Robert Francis, a barrister with significant experience of chairing inquiries, submitted a Memorandum to the Public Administration Select Committee which was deliberating on the Inquiries Act, in which he suggested that the benefits of public inquiries "must be weighed against the burdens that inquiries of any public nature place on those who are party to them, and the public in general".[66] Amongst the burdens he identified were the anguish of victims, the workload placed on public bodies and the impact on staff under investigation, as well as cost. He went on to chair a non-statutory inquiry into the Mid Staffordshire Foundation Trust and was subsequently appointed by the Labour government to chair a

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[63] First Minister's Question Time Meeting of the Parliament 20 November 2008, session 3, col 2168.

[64] S Carrell, 'Inquiry blames hospital for Cdiff deaths' <theguardian.com/society/2008/aug/08/mrsa.nhs> accessed 7 May 2020.

[65] L MacLean, *The Vale of Leven Hospital Inquiry Report* (APS Group 2014) 412.

[66] R Francis, 'Memorandum by Robert Francis QC' (GBI 06) in House of Commons Public Administration Select Committee, *Government Inquiry. Written Evidence* (The Stationery Office Ltd 2004).

more wide-ranging non-statutory inquiry into what had gone wrong at the Trust. However, Andrew Lansley, as Secretary of State for Health in the Coalition Government, decided it should be a statutory public inquiry. He gave as his reasons:

> This was a failure of the trust first and foremost, but it was also a national failure of the regulatory and supervisory system, which should have secured the quality and safety of patient care. Why did it have to take a determined group of families to expose those failings and campaign tirelessly for answers?[67]

However, the decision was probably political. Indeed there is considerable evidence to suggest that Public Inquiries usually have political motives behind them, whether in response to growing public clamour or, as was suggested by Marr about the Scott Inquiry set up by John Major: "The administration was so lacking in authority that it was protecting itself, for the time being, with the borrowed authority of Lord Justice Scott. The tougher the judge, the stronger the shield."[68] Significant support for such a view comes from the experimental work of Sulitzeanu-Kenan on a web-based study of 474 UK citizens.[69] Apart from blame avoidance the breathing space resulting from the inquiry process allows the significance of the event to move down the public agenda and so potentially limit the need for any active interventions. Against such a background Black and Mays have drawn attention to the formal absence of any method of assessing the impact of inquiries compared to their cost,[70] in other words whether they represent "value for money".

4. Statutory Inquiries and the BEM Community

Pressure groups, such as Cure the NHS, Tainted Blood and Factor 8, have been instrumental in bringing long-term pressure on governments to launch public inquiries into health issues. In the case of underserved ethnic minority groups a

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[67] HC Deb 9 June 2010, vol 511, col 333.

[68] A Marr, 'Behold the backlash, sabres drawn' *The Independent* (8 June 1995) <independent.co.uk/voices/behold-the-backlash-sabres-drawn-1585410.html> accessed 7 May 2020.

[69] R Sulitzeanu-Kenan, 'If they get it right: an experimental test of effects of the appointment and reports of UK public inquiries' (2006) 84 Public Administration 623.

[70] N Black and N Mays, 'Public inquiries into health care in the UK: a sound basis for policy- making?' (2013) 18 Journal of Health Service Research & Policy 129.

public inquiry will only be achieved through persistent, targeted and informed tactics. Recruitment of politicians and public figures as influential supporters is central to a successful approach.

The question then arises as to how likely it is that patients with disparate diseases from a range of minority communities could come together and develop such a strategy. Interestingly inquiries related to health issues have usually concerned one group of patients, such as haemophiliacs, or those infected by *Clostridium difficile*. In the case of infected blood products it affected thousands of people, whereas the two inquiries concerned with deaths from *Clostridium difficile* involved less than 70 patients.

Assuming that a substantial pressure group developed amongst BEM patients and the executive considered the issue of sufficient consequence to set up an inquiry what would be important aspects? Clearly chairmanship of the inquiry and its membership would be critical. The chair would ideally be a judge and membership should include those with legal, cultural and epidemiology backgrounds. Although choice of membership lies with the minister, it is the chairman, with advice from the inquiry solicitor and counsel, who designates core participants.[71]

5. Statutory Inquiries, the BEM Community and Core Participants

Core participants are defined in s 5(2) of The Inquiry Rules 2006 as:

a. the person played, or may have played, a direct and significant role in relation to the matters to which the inquiry relates;
b. the person has a significant interest in an important aspect of the matters to which the inquiry relates; or
c. the person may be subject to explicit or significant criticism during the inquiry proceedings or in the report, or in any interim report.

BEM patients would come under s 5(2)(b), whilst (a) and (c) would include such Trusts as Pennine Acute Hospitals NHS Trust, Barking, Havering & Redbridge University Hospitals NHS Trust and University Hospitals of Leicester NHS Trust. These three Trusts have underserved patients from the South Asian community who had inflammatory bowel disease.[72] In practice, core participants are often

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[71] P Skelton, 'The administration of an inquiry' in J Beer, J Dingemans and R Lissack (eds), *Public Inquiries* (OUP 2011) 156.

[72] Farrukh and Mayberry, 'Ethnic variations in the provision of biologic therapy for Crohn's disease: a Freedom of Information study' (n 11).

organisations representative of individuals rather than individuals, themselves. In the case of patients this could present an additional hurdle related to medical confidentiality and s 5(1) specifies that a person can only be designated as a core participant: “provided that person consents to being so designated”.

The advantages of being a core participant have been summed up by Sir Brian Langstaff, chair of the Infected Blood Inquiry. The inquiry will:

> engage with core participants on matters of practice and procedure which they will help to shape, and indeed will expect core participants to further the working of the Inquiry on an ongoing basis in ways that go beyond what it will ask of those who are not.[73]

Such views contrast with the status of infected patients who will simply “add to the Inquiry’s store of knowledge”.[74] Core participants will be able to:

c. suggest lines of questioning (normally through their recognised legal representatives) to be pursued by Counsel to the Inquiry;
d. apply through their recognised legal representatives to the Chair to ask questions of witnesses during a hearing;
e. have access to the expert groups (through the Inquiry Secretariat) and be able to propose experts to be added to those groups;
f. be provided, prior to publication, with a copy of the report (or any interim report) which is to be published.[75]

Langstaff is clear about the importance of the term “significant” in s 5 (2) of The Inquiry Rules 2006. As other chairs of statutory public inquiries, Langstaff will decide who can have Core Participant status. Such a role will inevitably help shape the proceedings and outcome of any inquiry. Clearly, in any inquiry into under-serving the BEM community the role of individual patient claimants will be limited. At best they will add to the narrative. The suggestion that organisations such as the Equality and Human Rights Commission will be able to act as Core Participants and speak on their behalf is undermined by its limited involvement with healthcare and unequal treatment related to protected characteristics. One of

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[73] B Langstaff, ‘Chair’s statement of Intent on Care Participant Status’ (2018) <infectedbloodinquiry.org.uk/sites/default/files/documents/Chairs-Statement-of-Intent-on-Core-Participant-Status-1.pdf> accessed 7 May 2020.

[74] <infectedbloodinquiry.org.uk> accessed 7 May 2020.

[75] B Langstaff, ‘Statement of Approach – Core Participant Status’ (2018) <infectedbloodinquiry.org.uk/sites/default/files/documents/Statement-of-Approach-Core-Participant-Status-1.pdf> accessed 7 May 2020.

the only examples of its involvement is related to hospitalised deaf patients.[76] Other potential Core Participants might include Monitor (now NHS Improvement), the Care Quality Commission, local Clinical Commissioning Groups and Health and Well-Being Boards as well as relevant Trusts. The track record of these organisations as far as BEM communities being underserved is non-existent.

Monitor's role was defined in the Health and Social Care (Community Health and Standards) Act 2003 as:

> 4 (b) reducing inequalities between persons with respect to their ability to access those services, and
> (c) reducing inequalities between persons with respect to the outcomes achieved for them by the provision of those services.

To date it has failed to publish any examples of having intervened to address inequalities in service delivery related to ethnicity. Similarly the Care Quality Commission (CQC) has failed in this area. In describing its work the CQC stated its objectives were to "help to focus providers and commissioners on the importance of their responsibilities towards equality, diversity and human rights", and to ensure that, "an organisation provides services proportionately to different groups and their needs".[77] However, it is yet to publish any outcomes of work on the health care of patients from the BEM community. Health and Well-Being Boards' role is advisory representing local groups but lacking any enforceable powers. In contrast Clinical Commissioning Groups are directly responsible for the purchase of appropriate care for patients in their locality and so share responsibility with NHS Trusts for ensuring equitable access to services and treatment. The Public Sector Equality Duty identified in the Equality Act 2010 is the basis for the statement in the NHS Constitution that:

> Legal duties require NHS England and each clinical commissioning group to have regard to the need to reduce inequalities in access to health services and the outcomes achieved for patients.[78]

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[76] Equality and Human Rights Commission, *Section 23 Agreement between The Equality and Human Rights Commission and Tayside Health Board This Agreement* (2014) <https://www.nhstaysidecdn.scot.nhs.uk/NHSTaysideWeb/idcplg?IdcService=GET_SECURE_FILE&Rendition=web&RevisionSelectionMethod=LatestReleased&noSaveAs=1&dDocName=prod_226503> (accessed 4 January 2021).

[77] Care Quality Commission <cqc.org.uk/content/about-us> accessed 7 May 2020.

[78] Department of Health, 'Guidance: The NHS Constitution for England' (2015) <gov.uk/government/publications/the-nhs-constitution-for-england/the-nhs-constitution-for-england> accessed 7 May 2020.

Such organisations are likely to be Core Participants. Their financial weight will give them a significant advantage in presenting and defending their case compared to the charities concerned with inflammatory bowel disease. In 2016 company accounts revealed that Crohn's & Colitis UK had assets of £3 million with an annual expenditure of £1 million[79] and charity returns for CICRA, the other self-help group, showed assets of £600,000 with an annual expenditure of £300,000.[80] Should a pressure group emerge from the BEM community its funding will be dwarfed in comparison to NHS related organisations. Nevertheless, it would be essential that patients are directly represented so they can help formulate the direction of any inquiry and have all the advantages of being Core Participants.

6. Statutory Inquiries and Duties of Confidentiality

Any organisation accused of underserving the BEM community will claim the information needed to answer questions is protected by medical confidentiality.[81] However, *Nicholas Lewis v Secretary of State for Health (defendant) & Michael Redfern QC (interested party)*[82] found that the public interest in disclosing medical records outweighed any interest in maintaining their confidentiality. A further significant issue when assessing differences in delivery of care would be the disclosure of records related to patients from the white community, who had received good quality of care. Only through such disclosures would it be possible to demonstrate underserving of one community compared to another.

7. Statutory Inquiries and Standard of Proof

To date, all academic publications on delivery of substandard care to BEM communities have involved case series, cohort or community based studies. They have demonstrated general attitudes rather than drilling down to individual cases. Clearly, any public inquiry into underserving of BEM communities would need to define the standard of proof which it would accept. To some degree this will be influenced by the possible consequences of an inquiry finding that there has been discrimination. The 2005 Act provides no guidance in this area of standard of

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[79] Crohn's and Colitis UK <beta.companieshouse.gov.uk/company/05973370/filing-history> accessed 7 May 2020.

[80] CICRA <cicra.org/media/1336/annual-report-2018.pdf> accessed 7 May 2020.

[81] J Beer, 'Evidence and Procedure' in J Beer, J Dingemans and P Lissack, *Public Inquiries* (OUP 2011) 193.

[82] [2008] EWHC 2196 (QB).

proof.[83] However, it needs consideration. For example, could such a finding be used as the basis for payment of compensation to individuals and families? In the Bloody Sunday Inquiry Saville L ducked the question, stating: "it seems to us that we can and should reach conclusions without being bound by rules designed for court cases, such as who has the burden of proof and the strict rules of evidence."[84] The situation may be easier in an inquiry into underserving of BEM communities as this would be a civil issue and "balance of probabilities" would be the standard.

8. Statutory Inquiries and the Consequences of Confirmation of Underserving BEM Communities

A statutory public inquiry can only make recommendations when required to do so by its Terms of Reference.[85] However, even then there is no requirement that Parliament takes any action on them.[86] From a patient's perspective a statutory public inquiry could be disappointing – an expensive and prolonged investigation with results which they already knew leading to no change. In 2002 Walshe and Higgins reviewed the impact of all forms of inquiry on the NHS and concluded that:

> The consistency with which inquiries highlight similar causes suggests that their recommendations are either misdirected or not properly implemented. Certainly there are few formal mechanisms for following up the findings and recommendations of inquiries. However, many of the problems identified by inquiries are cultural and demand changes in attitudes, values, beliefs, and behaviours—which are difficult to prescribe in any set of recommendations.[87]

There are no indications that the situation has improved and the need for changes in attitude remains a major stumbling block to reform. In the case of inflammatory bowel disease, publication of evidence of underserving of BEM

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[83] J Aiken, 'Inquiry reports and the duty to be fair' in J Beer, J Dingemans and R Lissack, *Public Inquiries* (OUP 2011) 370.

[84] L Saville, 'Standard of proof ruling' (2004) para 18 <webarchive.nationalarchives.gov.uk/20101103103956/http://www.bloody-sunday-inquiry.org/rulings/tribunal/Archive/proof.pdf> accessed 7 May 2020.

[85] s 24(1)(a) Inquiries Act 2005.

[86] Beer (n 27) 25.

[87] K Walshe and J Higgins, 'The use and impact of inquiries in the NHS' (2002) 325 British Medical Journal 895.

communities has achieved nothing. For example, when asked through a Freedom of Information request what had been done, University Hospitals of Leicester NHS Trust replied complacently:

> There is no intent within the Trust for there to be inequitable access by the South Asian Community and other community groups to treatment with biologics. Indeed, the service considers that as the population of Leicester has a white English minority with a very large South Asian presence, it would be both difficult and unlikely for there not to be equitable access to biologic therapy.[88]

In 2004 Sir Ian Kennedy, who chaired the Bristol Royal Infirmary Inquiry, confirmed that once its report is delivered an inquiry "ceased to have any standing".[89] As a result there was no mechanism for formal review of whether recommendations had been implemented, a suggestion, which the Executive, failed to incorporate into the Inquiries Act 2005. However, Rough[90] has pointed out that the more individuals who take part in the debate which surrounds an inquiry, the more difficult it becomes for the relevant industries, in this case the NHS, to insulate themselves from scrutiny.

NON-STATUTORY INQUIRIES

The decision whether an inquiry should be statutory or non-statutory is made after advice from the Cabinet Office Propriety and Ethics Team. In recent times non-statutory inquiries are held when matters of intelligence need to be considered *in camera*.[91] Their relevance, therefore, to underserved BEM communities may be questioned. However, prior to the Inquiries Act 2005 they were a popular method of reviewing problems within the NHS.[92] They continue to be used with a recent example being the investigation into the maternity and neonatal services at University Hospitals of Morecambe Bay NHS Foundation Trust.[93] The rationale

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[88] University Hospitals of Leicester NHS Trust, Freedom of Information Request GB/FOI/30912.

[89] I Kennedy, 'Government by inquiry' (2004) Question 654 <publications.parliament.uk/pa/cm200405/cmselect/cmpubadm/uc51-i/uc5102.htm> accessed 7 May 2020.

[90] E Rough, 'Policy learning through public inquiries? The case of UK nuclear energy policy 1955 – 61' (2011) 29 Environment and Planning C: Government and Policy 24.

[91] Caird (n 49) 6.

[92] Walshe and Higgins (n 87) 895.

[93] B Kirkup, *Morecombe Bay Investigation* (Stationery Office 2015) 1.

for the choice of a non-statutory inquiry is unclear, but it followed on from a failure by the CQC to identify and publish concerns about practices at the hospital. An earlier investigation by Grant Thornton had concluded:

> on the evidence examined it seems that an attempt to cover-up matters concerning CQC's regulation of UHMB may have taken place. The first improper action was the instruction to delete an important, internal report, which more likely than not, did occur.[94]

The issues at Morecambe Bay continued and one year after publication of his report, Kirkup was unhappy with the lack of progress.[95] This is not surprising as a review by National Audit found that only 45 per cent of recommendations made by inquiries were adopted by the Executive.[96]

Clearly, should an inquiry ever happen into underserving of the BEM community by the NHS it would need to be a statutory one with none of it *in camera*. Even then based on previous inquiries, on the balance of probabilities, it is unlikely to have any long-term impact on delivery of care to this community.

1. Judicial Review and Healthcare for BEM Communities

Public law challenges to decisions within the NHS have been uncommon and often unsuccessful.[97] One reason is the successful role of private law in the field of medical negligence, especially for after-the-event issues. However, public lawyers have contended that the courts have the capacity to play a more active role in 'refining the decision-making process, and consequently reducing any sense of unfairness and ultimately recourse to litigation'.[98] During the second half of the 20th century there has been a reorientation of judicial review away from the

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[94] Grant Thornton, 'The Care Quality Commission re: Project Ambrose' (2013) <cqc.org.uk/sites/default/files/media/documents/grant_thornton_uk_llp_morecambe_bay.pdf> accessed 13 January 2019. (This document can no longer be accessed but is referred to in many publications).

[95] S Lintern, 'Kirkup: Lack of progress since Morecambe Bay inquiry risks "disaster"' (2016) Health Services Journal. <https://www.hsj.co.uk/quality-and-performance/kirkup-lack-of-progress-since-morecambe-bay-inquiry-risks-disaster/7002897.article> accessed 4 January 2021.

[96] National Audit Office, 'Investigation into government-funded inquiries' (HC 836, 2017).

[97] P Bibby, *Effective Use of Judicial Review* (Tolley Publishing Company 1995) 98.

[98] R James and D Longley, 'Judicial Review and Tragic Choices: Ex Parte B' (1995) 367 Public Law 373; A Parkin, 'Allocating Health Care Resources in an Imperfect World' (1985) 58 Modern Law Review 867.

mediatory issues that had been the primary focus of the debate throughout the period leading up to the 1960s, towards a new and entirely 'public' task, namely, that of enforcing public duties.[99] Pressure groups, representative bodies and statutory organisations have liberal access to the courts for purposes of bringing proceedings in their own names or intervening as third parties in ongoing disputes.[100] Indeed, during the last five years a number of Claimants have sought judicial review against the NHS as a whole or against delegated bodies. This is not surprising considering Laws LJ's judgment in *International Transport Roth GmbH v Home Secretary* where individual rights were unqualified and the decisions taken had been made by unelected officials.[101] This can give rise to controversy when judicial decision-making fringes upon matters of policy;[102] the courts have noted that there can be merit in constraining decision makers even in those cases where no individual has been directly affected by a decision.[103]

JUDICIAL REVIEWS AND THE NHS

Topics have ranged from national contracts to individual concerns about current and future delivery of care. At times, the simple threat of action has resolved the problem. For example, in early 2018 the Equality and Human Rights Commission threatened action against 13 Clinical Commissioning Groups (CCGs) because of their Continuing Care policies on the basis that they were unlawful and breached the human rights of patients. The Commission's concerns related to arbitrary caps on funding and failure to consider specific needs of individual patients. However, no action was taken as the CCGs convinced the Commission that they were revising their policies.[104] In contrast, a number of pharmaceutical companies have

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[99] TT Arvind and L Stirton, 'The curious origins of judicial review' (2017) 133 Law Quarterly Review 91.

[100] *AXA General Insurance Ltd v Lord Advocate* [2011] UKSC 46, [2012] 1 AC 868; *Re E (A Child)* [2008] UKHL 66, [2009] 1 AC 536; for example, M Kirby, 'Deconstructing the law's hostility to public interest litigation' (2011) 127 Law Quarterly Review 537.

[101] [2003] QB 728, 765ff.

[102] C Harlow, 'Public law and popular justice' (2002) 65 Modern Law Review 1.

[103] *R v Secretary of State for Foreign and Commonwealth Affairs, ex p World Development Movement Ltd* [1995] 1 WLR 386, 395 (Rose LJ); *R v Somerset CC, ex p Dixon* [1998] EnvLR 111, 121 (Sedley J); G Anthony, 'Public interest and the three dimensions of judicial review' (2013) 64 Northern Ireland Legal Quarterly 125.

[104] Equality and Human Rights Commission, 'NHS U-turns on discriminatory policies' (2018) <equalityhumanrights.com/en/our-work/news/nhs-u-turns-discriminatory-policies> accessed 7 May 2020.

sought judicial review when policies constrained use of their drugs, in particular when there was an expressed preference for the products of a rival company. In 2018 Mrs Justice Whipple dismissed such an application in *Bayer Plc and Novartis Pharmaceuticals UK Ltd against Various Clinical Commissioning Groups*[105] for their policies on which drugs should be used to treat Age-Related Macular Degeneration. There would appear to have been no cases where judicial review has been sought in relation to delivery of care by NHS Trusts. The NHS's legal arm, NHS Resolution, reported only four cases where it acted as defendant, none of which concerned clinical care or involved NHS hospitals.[106] Against this background it is important to consider whether discrimination experienced by BEM patients in the form of substandard clinical care might be dealt with through judicial review.

POLICIES AND DECISION MAKING IN THE NHS

In 1995 Bibby discussed how decisions were made within the NHS.[107] Although policies were often published this was not always the case. There have been no suggestions of any written policies within certain NHS Trusts which would limit the number of South Asian patients receiving expensive biologic treatment or for any other form of discrimination against members of BEM communities. However, as Bibby suggested, there are occasions where the "existence of the policy is revealed only by analysis of the treatments actually given".[108] It was by such mechanisms that the under-treatment of inflammatory bowel disease amongst South Asian patients was first identified.[109] The "policy" may simply reflect the fact that some clinicians show significant racial bias, believing BEM patients are less likely to adhere to treatment and take personal responsibility for management of their disease.[110] It seems likely such attitudes may play a role in the underserving of patients with inflammatory bowel as they were seen less frequently by consultants, their management being left in the hands of junior doctors.[111]

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[105] [2018] EWHC 2465 (Admin).

[106] NHS Resolution (2019) <resolution.nhs.uk/pca-judgements> accessed 7 May 2020.

[107] Bibby (n 97) 98.

[108] Bibby (n 97) 98.

[109] Farrukh and Mayberry, 'Patients with ulcerative colitis from diverse populations: the Leicester experience' (n 12); Farrukh and Mayberry, 'Ethnic variations in the provision of biologic therapy for Crohn's disease: a Freedom of Information study' (n 11).

[110] NN Khosla and others, 'A comparison of clinicians' racial biases in the United States and France' (2018) 206 Social Science & Medicine 31.

[111] Farrukh and Mayberry, 'Patients with ulcerative colitis from diverse populations: the Leicester experience' (n 12).

CRITERIA FOR A JUDICIAL REVIEW AND AGAINST WHOM WOULD IT BE SOUGHT

54.1.1 of Civil Procedure Rules 1998 identifies:

> the principal questions which arise when deciding whether it is appropriate to bring a claim by way of a claim for judicial review, are namely:
>
> (1) Against which person or bodies does judicial review lie?
> (2) Is the measure, action or omission challenged one that is amenable to judicial review?
> (3) On what grounds does judicial review lie?
> (4) Who can apply for judicial review?

Civil Procedure 54.1.2 states that such a person can seek review against "any person or body performing public duties or functions" and that a claim for judicial review includes: "54.1 (2)(a)(ii) a decision, action or failure to act in relation to the exercise of a public function".

> The NHS Constitution sets out patients' rights and pledged the NHS to achieving them. The first principle was that the NHS should provide "a comprehensive service available to all".[112]

At the time the Lord Chancellor recognised that:

> Many of the entitlements under the NHS and the duties incumbent on public authorities are legally enforceable through the mechanism of judicial review of executive action of Strategic Health Authorities and Primary Care Trusts in England.[113]

However, many of the rights in the Constitution are more accurately considered as summations of multiple legal obligations arising from a range of sources. One

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[112] Department of Health, 'Guidance: The NHS Constitution' (n 78).

[113] Lord Chancellor and Secretary of State for Justice, *Rights and Responsibilities: Developing Our Constitutional Framework* (Ministry of Justice, The Stationery Office 2009) 44.

purpose of the Constitution is to empower patients and as such it has singularly failed. In the Third Report on its impact in 2019 it was noted that:

> In 2018, 19% of members of the public surveyed said that they had heard of the Constitution when prompted by a written description. This is a fall of 5% from the 2015 figure of 24% and an overall fall of 3% since 2009.[114]

In addition, the Court of Appeal has recognised in *Coughlan*[115] that as demand will always outstrip resources the NHS may never provide a comprehensive service, but rather the Secretary of State and NHS England have a **duty to promote** such a service. Indeed, s2 of the Health Act 2009 only imposes a duty on NHS bodies to have regard to the NHS Constitution.

In *R (Tracy) v Cambridge University Hospitals NHS Trust*[116] Lord Dyson MR underlined that having regard to the constitution only required that commending a joint statement was sufficient. In the context of inequitable care for members of the BEM community it could, therefore, be argued that a commitment by an NHS Trust to equality as a target would be sufficient. In fact, Green J in *R (Justice for Health) Ltd v Secretary of State for Health*[117] has described the duty to have regard to the NHS Constitution as a "target duty". However, Green J in *National Aids Trust v NHS England*[118] cited the Constitution as a "reinforcing factor" in reaching his conclusion that NHS England had misdirected itself in law. Such a use of the NHS Constitution has been made in other cases.[119] Its use, therefore, in the context of purposive constructions of NHS bodies' statutory and public law duties appears to be increasing.[120]

In the case of underserved patients from BEM communities judicial review would be sought against those Trusts where this was happening and against Clinical Commissioning Groups who dealt with them. Clinical Commissioning

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[114] Department of Health and Social Care, *Third Report on the Effect of the NHS Constitution* (2019) 6 <assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/770525/Statutory_report_on_NHS_Constitution_January_for_2019.pdf> accessed 8 May 2020.

[115] R v North and East Devon Health Authority, ex p Coughlan [2001] QB 213, [2000] 2 WLR 622, [2000] 3 All ER 850, 51 BMLR 1, [1999] Lloyd's Rep Med 306, 97 LGR 703.

[116] [2014] EWCA Civ 822.

[117] [2016] EWHC 2338 (Admin).

[118] [2016] EWHC 2005 (Admin).

[119] *R (Rose) v Thanet CCG* [2014] EWHC 1182 (Admin).

[120] H Gibbs, 'The purpose and effect of the NHS Constitution' (2017) <landmarkchambers.co.uk/resources/guide-to-the-law-of-the-nhs/> accessed 8 May 2020.

Groups have replaced Primary Care Trusts as the bodies through which local health needs are met. Clearly, it would be inappropriate to take action directly against the NHS as a whole as many Trusts provide an appropriate level of service.[121] Indeed in the case of inflammatory bowel disease six of the ten Trusts included in the study provided adequate care.

Trusts are required to collect data on ethnicity, admissions and procedures. This information is overseen by NHS Digital.[122] Although Freedom of Information (FOI) requests are powerful tools for obtaining access to these data, responses are at the discretion of the local officer dealing with them and some claim that they do not collect such data as happened with Bradford.[123] In addition, Bourke et al. have shown that FOI officers are more inclined to help applicants they know and consider friendly.[124] It is unlikely that a patient or group concerned with underserving of the BEM community would fall into such a category.

IS THE OMISSION CHALLENGED AMENABLE TO JUDICIAL REVIEW?

English public law allows courts to control failures in the performance of public duties. s2 and s14 of the Human Rights Act 1998, which embody the right to life and not to experience discrimination, can form the basis for seeking judicial review (CPR 54.1.9). In addition s6 specifies that it is unlawful for a public body to act in a way incompatible with a Convention Right. The Human Rights in Healthcare Programme of the NHS recognised the impact of the Act in 2011 when it published Guidance Notes which included the statement: "Policies and the practice of care should be non-discriminatory and pay particular attention to ensuring that standards are equally high for all individuals concerned."[125] It is of concern that the program was suspended in January 2013 because of lack of funding! Some nine years later its webpage states: "The programme is on hold (January 2013) until continuation funding is found."[126] There is no indication that this will happen and the program be revived.

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[121] Farrukh and Mayberry, 'Ethnic variations in the provision of biologic therapy for Crohn's disease: a Freedom of Information study' (n 11).

[122] <digital.nhs.uk/data-and-information> accessed 7 May 2020.

[123] Farrukh and Mayberry, 'Ethnic variations in the provision of biologic therapy for Crohn's disease: a Freedom of Information study' (n 11).

[124] G Bourke, B Worthy and R Hazell, *Making Freedom of Information requests. A guide for academic researchers* (University College, London, The Constitution Unit 2012) 7.

[125] <humanrightsinhealthcare.nhs.uk/Library/az/Human_Rights_Survey_Hospital_Patients_Guidance_Notes.pdf> accessed 17 January 2019. (site not secure on 7 May 2020).

[126] <.humanrightsinhealthcare.nhs.uk/About-Us/default.aspx> accessed 7 May 2020.

ARE THERE GROUNDS FOR JUDICIAL REVIEW?

The European Convention on Human Rights does not specifically refer to health issues. However, there have been cases which confirm that they can be considered. For example, in *Turkey v Cyprus* the Court reviewed access to health care but held that "no violation of Article 2 of the Convention has been established by reason of an alleged practice of denying access to medical services to Greek Cypriots and Maronites living in northern Cyprus".[127] In considering how Turkey dealt with its own nationals in *Şentűrk & Şentűrk v Turkey* the Court*:*

> reiterates that the first sentence of Article 2 § 1 enjoins the State not only to refrain from the intentional and unlawful taking of life, but also to take appropriate steps to safeguard the lives of those within its jurisdiction. These principles apply also to the area of public health …. It cannot be excluded that the acts and omissions of the authorities in the context of public-health policies may, in certain circumstances, engage their responsibility under the substantive limb of Article 2.[128]

The Court has begun to recognise the right of access to healthcare and that it should be of a certain quality. Following on from *Atiman v Turkey* the Court made it clear that Article 2 was not restricted to cases where there had been a death but also "where the alleged victim had not died as a result of the impugned conduct".[129] Such cases are a significant movement towards "more substantive justiciable protection" for underserved patients.[130] Clearly the underserving of BEM patients would be an omission that could be brought forward for judicial review. In contrast to the care concerning Greek Cypriots and Maronites in Northern Cyprus the evidence for reduced access to healthcare is robust.

The Equality Act 2010 and the public sector equality duty (PSED) make it incumbent on the NHS to deliver equal care to all sectors of British society and this has been recognised in the advice it gives: 'Members of the public could seek judicial review of a breach of the PSED by either the Health Body or the third party.'[131]

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[127] *Turkey v. Cyprus* App no 25781/94 (ECtHR, 2001) para 221.

[128] *Mehmet Şentűrk & Bekir Şentűrk v. Turkey* App no 13423/09 (ECtHR, 2013).

[129] *Atiman v. Turkey* App no 62279/09 (ECtHR, 2014).

[130] L Graham, 'The European Court of Human Rights and the emerging right to health' (2017) Oxford Human Rights Hub <ohrh.law.ox.ac.uk/the-european-court-of-human-rights-and-the-emerging-right-to-health> accessed 7 May 2020.

[131] NHS Centre for Equality and Human Rights, *The Public Sector Equality Duty and Third Party Service Providers* (2012) <wales.nhs.uk/equality> accessed 7 November 2018. (No longer available).

WHO COULD APPLY FOR JUDICIAL REVIEW OF REDUCED ACCESS TO HEALTHCARE?

Any person or legal person applying for judicial review of underserving of South Asian patients will need to demonstrate that they have standing. Section 31 (3) of the Senior Courts Act 1981 states that "the applicant has a sufficient interest in the matter to which the application relates".

CPR 54.1.11 recognises that if a claimant has a direct personal interest in the outcome of a claim this would be sufficient. In recent years a liberal attitude has been taken towards public interest groups representing communities or issues. Essentially the court makes its assessment through a two-stage process:

1. At the permission stage the claimant must show he has sufficient interest.
2. At the substantive hearing claimants must demonstrate they have "sufficient interest to maintain their claim for a particular remedy". (CPR 54.1.11)

Interestingly, the applicant need not personally have experienced adverse consequences of a government body decision, but simply be at 'risk of being directly affected'.[132] However, with under-delivery of care to a whole community it might be argued that if the applicant had himself received poor care this was a matter for private law and so outside the scope of judicial review. In recent cases when this distinction was unclear, the trend has been to commence proceedings.[133]

Patients from the BEM community could base their application on a Trust's failure to fulfil a legitimate expectation. Their treatment had been simply unfair. In *R v Devon County Council ex p Baker* Brown L stated:

> the claimant's right will only be found established when there is a clear and unambiguous representation upon which it was reasonable for him to rely. Then the administrator or other public body will be held bound in fairness by the representation made unless only its promise or undertaking as to how its power would be exercised is inconsistent with the statutory duties imposed upon it.[134]

Equality in delivery of health care falls squarely within this definition.

The discovery of discrimination in delivery of care has arisen out of academic research, but this has not excluded administrative courts giving guidance to

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[132] *Norris v Ireland* App no 10581/83 (ECtHR, 1988).

[133] H Southey and others, *Judicial Review: A Practical Guide* (LexisNexis 2017) 214.

[134] [1995] 1 All ER 73.

decision-makers. This was often through *obiter* remarks but also included granting individuals' relief.[135]

During the last 20 to 30 years declarations have frequently been sought by NHS Trusts to allow them to withdraw life support from patients; a declaration requiring a Trust to deliver equality of care would carry equal weight and equivalent newsworthiness.[136] Although remedies granted to successful claimants are normally non-coercive declarations that public authorities are trusted to respect, where the BEM community has been shown to be underserved it is to be hoped that the court would issue a Mandatory Order and require the Trust to remedy its decision-making processes and comply with its statutory duties. Indeed, work by Platt et al. on local authorities has shown that "increases in challenge appear to be connected to improvements in quality scores, and are not simply the consequence of lawyers making work for themselves. The findings provide a quantitative basis for arguing that judicial review challenges may contribute to improvements in local government services and therefore that the effect of judicial review is neither insignificant nor wholly negative".[137]

POTENTIAL LIMITATIONS OF JUDICIAL REVIEW IN RESPONDING TO UNDERSERVING OF THE BEM COMMUNITY

There are several issues which limit the potential role of judicial review in this area. According to CPR 1998 r54.5 a claim form must be filed "not later than 3 months after the grounds to make the claim first arose". However, those grounds might not be recognised for a considerable time and then only through a Freedom of Information request. Such a request should be dealt within 20 working days, although the Information Commissioner can allow extensions of up to 40 days.[138]

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[135] Southey and others (n 133).

[136] D Sokol, '*Aintree University Hospital NHS Foundation Trust v James*: Best Interests and Futility under the Judicial Microscope' (2013) Journal of Medical Ethics <blogs.bmj.com/medical-ethics/2013/11/14/aintree-university-hospital-nhs-foundation-trust-v-james-best-interests-and-futility-under-the-judicial-microscope> accessed 7 May 2020.

[137] L Platt, M Sunkin and K Calvo, 'Judicial review litigation as an incentive to change in local authority public services in England and Wales' (2009) ISER Working Paper Series, No 2009-05, 16 <https://www.iser.essex.ac.uk/files/iser_working_papers/2009-05.pdf> accessed 7 May 2020.

[138] ICO, *Time Limits for Compliance under the Freedom of Information Act (Section 10)* <ico.org.uk/media/for-organisations/documents/1165/time-for-compliance-foia-guidance.pdf> accessed 7 May 2020.

For an individual patient who has received substandard care which caused him injury the case would come under private law and compensation would need to be sought under the tort of negligence. Even though costs can be limited through a Protective Cost Order, they are likely to be a factor-limiting individuals and pressure groups taking action.

Possible Actions by BEM Patients Under the Tort of Negligence

Where an individual has received sub-standard care which has caused him or her harm then an action under the tort of negligence would be likely to succeed and should form the basis for advice given to a client/patient. However, for family and others who know BEM patients, who have received sub-standard care, it is appropriate to consider whether there might be grounds for seeking compensation under the criteria laid out for nervous shock in *Alcock v Chief Constable of South Yorkshire Police*.[139] They are that: relatives must have a relationship of love and affection with the primary victim, have direct perception of the event with unaided senses, as well as have proximity to the event or its immediate aftermath and experienced psychological injury via a single nervous shock.

The distinction between the incident at Hillsborough which was sudden, fatal and public and the chronic illness of someone with inflammatory bowel disease is clear. However, close family members, in particular, will perceive the on-going events of sub-standard care and will be in close proximity to the aftermath of such poor care. Nevertheless in *Alcock* the judges defined an event as a single incident which occurred at a single moment in time, so excluding potential claims by families of chronically underserved patients.

The issue as to whether there can be sufficient proximity when there is a significant gap between a breach and any consequent injury has not been adequately addressed. This would be the case where a patient experienced significant injury because of chronic under management of his disease.[140] However, this view is not supported by *Sion v Hampstead Health Authority*[141] where a father watched his son gradually deteriorate and die over 14 days due to hospital negligence. The case was struck out by Staughton LJ on the basis that "the report describes a process

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[139] [1991] UKHL 5.

[140] J De Bono, 'Nervous shock and delayed injury' (2018) <ukhealthcarelawblog.co.uk/rss-feed/91-nervous-shock-and-delayed-injury> accessed 7 May 2020.

[141] (1994) EWCA Civ 26.

continuing for some time, from first arrival at the hospital to the appreciation of medical negligence after the inquest".[142]

On 13 October 2015 Andy McDonald attempted to address these issues through a Private Members Bill, which proposed that it was not a condition of the claim's success that the illness was induced by a shock, or that the claimant was close in time and space to the act or omission which causes the death, injury or imperilment of the immediate victim.[143] However, the Negligence and Damages Bill failed due to ending of the Parliamentary Session.

Overall, however, the courts and judicial review are increasingly retracing the reasoning processes of public bodies so as to ensure that decisions were not made in an arbitrary or thoughtless way – something which is true of inequitable delivery of care.

CONCLUSIONS AND RECOMMENDATIONS

Recently David Williams, Professor of Public Health at Harvard, asked: "How is it possible that people with good intentions seeking to do their best can nonetheless, at an aggregate level, create a pattern of care that is so discriminatory?"[144] He went on to say: "Our answer was implicit bias. It's also called unconscious or unthinking discrimination".[145] When such attitudes are widespread in an organisation it leads to "institutional racism" as defined by MacPherson in *The Stephen Lawrence Inquiry*.[146] Most attempts to deal with such issues have been outside of the UK, in countries such as the USA, Canada, Australia and New Zealand and largely dealt with the problems of indigenous minorities rather than migrant communities. They have largely been concerned with education and attempting to change the ethos of hospitals or public health services. It is now more than 50 years since Dr King made his plea for equality in healthcare. It was recently suggested that it may well be a further 50 years before it becomes a reality in the

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[142] ibid.

[143] Negligence and Damages HC Bill (2015–16) <publications.parliament.uk/pa/bills/cbill/2015-2016/0076/15076.pdf> accessed 7 May 2020.

[144] Harvard Institute for Healthcare Improvement, 'Does Racism Play a Role in Health Inequities?: A Conversation Between Donald Berwick, MD, and David R. Williams, PhD, MPH' (2018) <ihi.org/Documents/OpenSchoolCourseTranscripts/David-Williams-Don-Berwick-Does-Racism-Play-A-Role-In-Health-Inequities.htm> accessed 7 May 2020.

[145] ibid.

[146] Home Office, *The Stephen Lawrence Inquiry* (n 19).

USA.[147] The contention of this paper is that education and social programs have failed. Therefore, different approaches are needed. For individuals there can be redress through the courts for negligent care, but the issue is wider affecting whole communities and so requiring a broader approach. Such an approach would need to investigate both the causes of the problem, as well as its magnitude, and suggest methods by which the issue can be addressed.

Despite clear, published, widespread evidence that patients from BEM communities are underserved, this discrimination is recognised within the NHS by very few and there has been no co-ordinated and effective program to address the issue. The fact that the Human Rights in Healthcare Programme has been suspended for more than six years, because of lack of funding, emphasises the complacency within government and the NHS. This same culture also responds to other medical scandals with a similar complacency or, perhaps, indifference. Despite many recommendations from numerous inquiries across a number of medical areas the same issues regarding sub-standard care recur. The recent scandals at Morecombe Bay and Mid-Staffordshire Foundation Trust identified lack of staff, poor training, defective equipment and an inability to recognise that things had gone wrong as major components to the defective care provided by these Trusts. In the case of Morecombe Bay there was also evidence of a deliberate cover-up by the Care Quality Commission (CQC), which is the statutory body which should monitor performance. The situation with regard to discrimination in the delivery of care is no different. Trusts, Clinical Commissioning Groups and monitoring bodies, such as CQC and NHS Improvement, have failed to respond to published evidence of discrimination in the delivery of care. For these organisations education has had no impact and the Equality and Human Rights Commission has seldom involved itself on behalf of patients. The only approach likely to have any impact will be a legal one with individuals and institutions identified and held responsible for their actions.

The advantage of judicial review would be that individuals and institutions could be named and ordered to fulfil their statutory duties and deliver equitable care to the BEM community. However, it would deal with the issues on a case-by-case basis and only with time hopefully help change the culture across the NHS. A statutory inquiry could also require the attendance of witnesses and the disclosure of documents, but would be unable to enforce its recommendations and many would be concerned that the controlling hand of the Executive might lead to the effective suppression of evidence.

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[147] D Munro, ‘The 50th anniversary of Dr King’s healthcare quote’ *Forbes* (25 March 2016).

Although a Royal Commissions lacks coercive powers, because of its nature it is prestigious. As with Statutory Inquiries it cannot institute legal action against offenders, but its inquiries can be wide ranging and it should be free of political control once active. Unlike non-statutory inquiries its report will not be "lost" from the public arena. As Saatchi has argued, it is only through the "independence and thoroughness" of a Royal Commission that there can be a "sustainable policy change in the NHS"[148] and so reverse its institutional racism. However, on an individual basis, BEM patients who have received sub-standard care need to look at more traditional routes to seek redress and that must be through actions in the tort of negligence.

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[148] Saatchi (n 45) 29.

REVIEW

Gastroenterology and the provision of care to Panjabi patients in the UK

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Summary

Panjabi is spoken by 1.3 million people in the UK. It is the second most common language used in the country and is the first choice of 75% of Panjabis. It is becoming more common. For many patients it forms part of the barrier which limits access to gastrointestinal services. The provision of appropriate support services is woeful and yet seldom leads to formal complaints. This review considers the impact of gastrointestinal disorders on the Panjabi community and assesses some of the interventions that could be developed to ensure equity of care.

Introduction

At the beginning of the 21st century it was estimated that 1.3 million people in the UK spoke Punjabi, or more correctly Panjabi. This makes it the second most common language in the country.[1] Ethnologue estimates that for more than half a million people it is the first choice.[2] Panjabi continues to be important for the younger generation. In 2008, 1000 students took it as a GCSE subject and for 75% it was their mother tongue.[3 4] Its significance for the healthcare system is the need to ensure that communication is both understood and effective. Ethnic inequalities in health and healthcare are marked with language being a key barrier to accessing services.[5] Communication is, of course, a two-way process. Panjabi patients are likely to feel isolated and anxious. Can they make themselves understood? If a translator is used can they be assured that their answers will be treated in confidence? This is especially worrying if patient and translator know each other or live in similar areas of a town. This is even more so when a friend or relative is used in the consultation—a practice that is not uncommon in cash-strapped health units. In 1999 the Advisory Committee on Resource Allocation tried to overcome these restraints through:

'the introduction of an English Language Difficulty Adjustment (ELDA) for the extra costs of interpretation, advocacy and translation services.'[6]

However, in 2009 ELDA was abolished. In 2011 the National Health Service established *Race for Health* to support and challenge its organisations in tackling health inequalities.[7] It recognised that key indicators of which commissioners need to be aware include:

- ethnic and age/sex profile of local and national populations;
- health experience or services used, expressed using the same ethnic coding as that of the local/national population.[8]

This document acknowledges the need for community involvement, but no specific gastrointestinal diseases are considered within it and there are no examples of gastroenterologists dealing with issues of ethnicity and disease prevention or treatment. The situation was well summarised by Caroline Wright when she wrote for the BBC:

'Although this is something often deemed controversial, poorer health outcomes, decreased comprehension of diagnoses and reduced satisfaction with care are all associated with limited English proficiency and cannot be ignored.'[9]

Indeed the General Medical Council puts the onus on all doctors to ensure that:

'You must make sure, wherever practical, that arrangements are made to meet patients' language and communication needs.'[10]

The Medical Protection Society underlines the importance of such an approach and acknowledges that:

'Studies have shown that the use of professional interpreters improves care for patients with limited English proficiency. Patients who rate their translator highly

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are more likely to rate their healthcare highly. Yet around the UK, the provision of and access to these services is inconsistent.'[11]

It draws attention to the National Register of Public Service Interpreters, which provides a quality-assured register of healthcare interpreters, although it does not regulate them.[12]

The Panjabi community in the UK

Panjabis first came to the UK in significant numbers as a result of World War 1. However, the main migrations followed World War 2 and the division of Punjab between Pakistan and India. These migrants came largely to work in the construction industry. In the 1950s and later there were significant migrations from East Africa. A later group came from Afghanistan and work and live around Southall.[13] The Muslim Panjabi community largely lives around Birmingham, Bradford and Oldham.[14] Sikhs are most commonly found in Birmingham, Ealing (Southall), Sandwell, Hounslow, Wolverhampton, Coventry, Redbridge, Leicester, Hillingdon and Slough.[15]

Panjabi is spoken by Sikhs, Muslims, Hindus and Christians. It has two main dialects—Western and Eastern—and these largely correspond with the division of Punjab between India and Pakistan. Within Panjabi there are various dialects, such as Mirapuri and also distinct languages such as Saraiki.[14] There are no readily available data on the number of Saraiki speakers in the UK. It differs radically from the Panjabi of Lahore. In 1886 the British began a massive canal building programme in the Saraiki area of western Punjab and used Panjabis from the central part of the country as the workforce. Internal migration continued until the 1950s.[16] For both clinicians and translators recognition of these linguistic differences is important for accurate and effective communication.

The incidence of Panjabi as the preferred language was reviewed in Middlesbrough in 1998. Only 5% of patients were told of the availability of professional interpreters, and none used the service.[17] This observation has a direct link to contemporary work on the epidemiology of inflammatory bowel disease in the area.[18] Three per cent of the population came from an ethnic minority and a poorer quality of life was clearly linked to social deprivation.[19] Work by the Tees Valley Joint Strategy Unit identified the local Pakistani community as having multiple indicators of a lower standard of living.[20] This would suggest that Panjabi patients with inflammatory bowel disease often come from groups with a poorer quality of life and tend to accept limited clinical services. Similar aspects of social deprivation were reported in a study of coronary artery disease. They included length of working day, low income, crowded housing, liability to attack and perceived lack of social support (women).[21] It is not surprising that it is often a simple lack of knowledge which limits a community from making best use of facilities.[17] However, the onus lies with the provider to ensure that the community is aware of these services. Use of written material is inadequate. In the West Midlands fewer Panjabis could write English (41%) than speak it. Of those who could write English, only 63% considered that their standard was good, with fewer women than men able to do so (37% vs 53%).[21] Any use of literature in Panjabi needs to recognise the different scripts used by Muslim and Sikh communities, as well as the existence of distinct languages such as Saraiki. It must be tested on a group of patients before release.[22]

Gastrointestinal disease in the Panjabi community in the UK

Diseases tend to differ in their prevalence between communities in their home country and those living in a host country. With each generation there is a movement towards the prevalence seen among the indigenous population in the host country and at times to exceed it. This has been demonstrated among migrants from South Asia to Canada.[23] A recent study from Aberdeen, Dundee and Glasgow in 2009 showed that 20% of 111 people of South Asian origin, including Panjabis had gastrointestinal disease,[24] In this review we will consider the occurrence of gastrointestinal diseases in both the Punjab and the UK.

Gastrointestinal cancer

A study from Luton explored the meanings of cancer and perceptions of cancer services among South Asians living in Luton. Focus groups included Panjabi-speaking Muslims originating from Pakistan and a separate group of Sikhs originating from the Indian Punjab. Overall, participants in the study expressed a keen desire for the information relating to cancer to be made available through their community social networks. The lack of information resulted in low levels of awareness and cancer was often perceived as an incurable disease. This reflected the fact that access to appropriate services had been at a relatively late stage of the illness.[25] This study from 2004 emphasised the need for education which can influence how people manage cancer and access cancer services. In addition, a study of breast cancer among Panjabi women suggested that it was seen as a family event and models of care need to be family centred as well as culturally appropriate.[26]

Oesophageal and gastric cancer

Traditionally, gastric and oesophageal cancer were considered relatively uncommon in Punjab and this was attributed to the infrequent use of betel nut or paan by this community.[27] However, a recent study from Rawalpindi of ex-servicemen and their dependants from a rural area in Northern Punjab showed that oesophageal cancer tended to be commoner in women and gastric cancer in men.[28] Fourteen per cent of the patients with gastric cancer in the study were under the age of 40 years at the time of diagnosis. Most patients worked in the farming industry and it was suggested that exposure to an unknown source of fertilisers or radioactivity might be aetiological factors. Work on nitrate contamination of well water in farms across Muktsar, Bathinda and Ludhiana districts of Punjab suggested that this could play a part.[29] In 2011 there was evidence that the wells of Bathinda were also contaminated by uranium[30] as was the food.[31] Other work has shown arsenic to be a significant contaminant.[32] These changes mean that gastro-oesophageal cancer should be seriously considered when there is an appropriate history among young patients who are recent migrants from both West and East Punjab. This experience is in contrast to the general experience of falling gastric cancer rates.

Colorectal cancer

Traditionally colonic cancer was thought uncommon in the Punjab.[33] Mahotra suggested that this was the result of a diet rich in roughage, including cellulose, vegetable fibre and short chain fermented milk products. This was reflected in the low mortality figures reported for Panjabi migrants to the UK in 1984.[34] However, in 2005 the Punjab Cancer Registry was established and its initial reports dealt with Lahore where colorectal cancer is now the fourth commonest cancer, representing 3.25% of the total cancer load.[35] Interestingly, in the UK there is a suggestion that the relative incidence of colorectal cancer in the younger age groups is increasing and there is likely to be a significant jump in the number of cases of colorectal cancer identified in the Panjabi community.[36] A subsequent study has shown that these younger Asian patients tend to present later with more advanced disease.[37]

Pancreatic cancer and chronic pancreatitis

Studies from the cancer registries in the Indian subcontinent suggest that pancreatic cancer is uncommon.[38] However, in 1999 an increased risk of pancreatic cancer in migrant Panjabis in the UK was recognised.[39] This trend is consistent with other migrant studies of pancreatic cancer among South Asians.[40] Among Panjabis chronic pancreatitis is not uncommon, with 38% of cases related to alcohol.[41] The majority (95%) of patients present with abdominal pain and calcification of the pancreas is frequent.

Clearly, alcohol has an established role in the development of chronic pancreatitis. In a survey of four villages in Punjab 78% of the population used alcohol.[42] A later study reported that 11% of users were alcohol dependent.[43] During the 1990s and 2000s alcohol consumption increased enormously in the state of Punjab. In a survey by the Institute for Development and Communication over 60% of households were affected by alcohol abuse.

Over two-thirds of the victims were regular alcohol users and 26% recreational drug users.[44] Although these studies were conducted in India, alcoholism is also a problem among Panjabi Muslims and has been reported from Lahore.[45] Patterns of regular drinking by Sikh men are seen in the UK.[46] In a study of the Panjabi community of Metropolitan Toronto increased levels of acculturation were associated with increased lifetime use of alcohol and more liberal attitudes toward the use of alcohol. Those who had lower levels of acculturation experienced more alcohol-related problems. This was particularly true for men.[47] In the UK consumption is higher in Sikhs than in Hindus or Muslims, and heavy spirit drinking appears to be especially common among Sikh men.[48] In a qualitative study from the West Midlands wives and daughters of men with recognised alcohol problems initially resigned themselves to the problem and later defended their husbands or fathers.[49]

Inflammatory bowel disease

The Panjabi community is at an equivalent risk of developing inflammatory bowel disease (table 1). Indeed there is good evidence that the risk is probably greater than for the indigenous population of the UK. Reports from the British Cohort[54] and Leicester[55] show that Asian young people born in the UK are at even greater risk of developing ulcerative colitis and this is likely to be more severe than among other young people in the country. It is possible that changing social practices may play some role. For example, betel nut chewing seems to offer some protection against ulcerative colitis,[56] whereas the use of recycled cooking oils seems to be linked to a greater risk of developing Crohn's disease.[57] A recent study from Uttar Pradesh in India would suggest that any patient from India or Pakistan who works with animals and is suspected of ulcerative colitis or Crohn's disease should be tested for *Mycobacterium avis* subspecies *paratuberculosis* (MAP). Fifty per cent of goat herds who were suspected of Crohn's disease were positive for MAP on stool culture and this was particularly so in those with abdominal pain and diarrhoea. The longer the exposure to goats the higher the risk.[58]

In a study from the Punjab all patients with ulcerative colitis felt that allopathic medication was the best treatment, but a significant number (81%) reported use of some form of non-allopathic treatment in the previous 3 years. Thirty per cent were using these in addition to allopathic drugs. Forty patients (28%) had resorted to homoeopathy, 20 (14%) to ayurvedic, and 58 (41%) to indigenous medication during their disease.[59] There is evidence that this is also true in the UK.[60] In addition to the use of complementary therapy there is a tendency towards significantly low levels of adherence to 5-aminosalicylic acid treatment among patients of South Asian origin. This has been reported in studies both from India[61] and the UK.[62]

Coeliac disease

In 1993 Panjabi migrants living in Leicester were recognised as being at high risk of coeliac disease. The incidence of the disease was four times greater than among English inhabitants and eight times greater than among Gujaratis.[63] In the 1970s there had been an indication that coeliac disease might be commoner among Panjabis than originally thought. In Birmingham Nelson *et al* had reported coeliac disease in 17 children of migrants from the Punjab.[64] Clinical presentation for Panjabi patients is often associated with vitamin D deficiency, a high alkaline phosphatase and iron deficiency.[65] For Panjabis a gluten-free diet can present problems. It can affect family life and can set the patient aside from other members of the community, presenting particular difficulties at communal events. Educational material in Panjabi is limited and a study of 40 patients from the West Midlands has shown that they were less likely to attend dietetic clinics, join the Coeliac Society and be satisfied with information provided by doctors and dieticians than the indigenous population.[66]

Disease prevention

There is recent evidence that patients from ethnic minorities show significant differences in access to, and uptake of, cancer screening. Breast and cervical cancer screening are well established in the UK, but figures consistently show a lower uptake by ethnic minorities and is particularly low in the Muslim population. Four out of ten women opt out of both breast and bowel cancer screening and there also appears to be difficulty in ensuring continuity of uptake.[67] Despite these limitations in the provision of care few patients from a Punjabi background complain.[68]

Colorectal cancer screening

The UK colorectal cancer screening pilot programme among the general population reported an overall uptake of 62% for faecal occult blood testing (FOBT) for English people. This was considered acceptable, but uptake was low in the South Asian community, with figures for Muslims as low as 32%.[68] In the general population the uptake of FOBT screening was two and a half times lower among Muslims and Sikhs. Colonoscopy uptake rates were also significantly lower among Asians (55%) compared with 74% for non-Asians.[69] A study from the USA suggested that low uptake of screening for colorectal cancer in the general population may be due to a lack of awareness and inadequate provider counselling rather than a poor acceptance of the scheme.[70–72] To encourage participation and improve compliance, recommendation by a doctor was suggested to have a major impact.[73–77] These findings have been confirmed in the colorectal cancer screening program in the UK where Sikhs and Muslims have the lowest uptake rates. This may also, in part, reflect a lower level of confidence in the procedure than among White Europeans.[69] At present the main response to this issue has come from the voluntary sector. The charity, Bowel Cancer UK, has produced a short DVD in which South Asian actors discuss the risk of bowel cancer, how to reduce the risk, and screening (the faecal occult blood test). However, the DVD, which is entitled *Sehat Apni Apni* (*Our Own Health*), is in English with the option to watch it dubbed into Hindi or Punjabi.[78]

Development of a better model of care

Following the passing of the Race Relation Amendment Act 2000, it is a statutory duty on all NHS agencies to 'have due regards to the need to eliminate unlawful discrimination' and maintain racial equality. Availability of care is a function of the interaction between provider services, users and planners. Quality of care is defined as client-centred services, meeting their needs and expectations. It is a continuing process that incorporates patients' rights and their satisfaction with the system. It entails access to accurate, appropriate, understandable and unambiguous information at convenient times with no physical barriers. It helps patients make a well-judged decision based upon information, understanding and options that is informed choice rather than coercion. It embodies the concepts outlined in *Equity and Excellence. Liberating the NHS.* This document centres on the concept of 'no decisions about me without me.'[79] The unmet needs of migrants has been well demonstrated in a study of Panjabis aged between 19 and 90 in British Columbia.[80] Participants discussed unmet healthcare needs as related to a variety of aspects of accessibility including: lack of choice in the gender of a provider, particularly for women preferring to have a female doctor or a lack of a primary healthcare provider who was accepting new patients and spoke Panjabi. Without these basic provisions we will be unable to provide a gastroenterological service which involves patients in effective decision-making.

A study among Panjabi women living in British Columbia has shown that translations alone will not meet their needs. The community needed to be made aware of the role of prenatal preparation so that it could endorse women's participation. The solution was to bring representatives from a variety of service agencies together with members of the community. It also needed 'buy-in' from the doctors serving the women of the community.[81] The need for community and family involvement has also been seen in studies among Panjabi women with breast cancer.[26] The role of simple education is probably limited. For example, in a study of glycaemic control among Pakistani women from South Wales following an educational intervention, illiterate patients did not do as well as their literate peers, continuing to score less on knowledge parameters. They also did not show an improvement in glycaemic control.[82]

In studies from Middlesbrough written information in minority languages, professional interpreters, examination of female patients by women doctors and culturally suitable food were confirmed as priority needs. Staff training and community education was seen as essential to the successful implementation of better care for patients of Panjabi and other groups.[17] [68] People with limited command of English find it

Table 1 Inflammatory bowel disease and intestinal tuberculosis amongst Panjabis in India and the UK

Disease	Location	Period	Incidence (cases/10^5/year)	Reference
Ulcerative colitis				
	Punjab	1990s	6	50
	Leicester	1980s	16.5	51
Crohn's disease				
	Leicester	1980s	3.4	52
Abdominal tuberculosis				
	Leicester	1980s	8.7	53

difficult to obtain adequate healthcare and health information. Language barriers mean that they have insufficient knowledge about the range of health services available, and very little health-related information meets their individual language needs.[83] The use of telephone translation services is a poor substitute for the provision of a truly patient-centred service. They will be used by patients when no alternative exists but the practical difficulties associated with them, the impersonal nature of the service and the selecting out of people who need them as 'different' compromises every aspect of high-quality care. In addition, the belief that these problems will disappear with time owing to the absorption of a migrant community into the host community is not substantiated by research. In a study from Glasgow long-established residents had consistently worse results. More were overweight, reported heart trouble and respiratory conditions, had had accidents, needed glasses and took time ill in bed. It was unlikely that these results are explained by positive selection of recent migrants. These results did not endorse the assumption that the UK environment had promoted higher levels of health in migrants longer exposed to it, nor that the stress of a move promotes higher levels of illness in recent migrants.[84]

Any new model for the care of Panjabi patients' needs to bridge the gap between provider opinion and users' perceptions of the service. The best prospect for achieving this outcome is likely to be through use of participatory meetings and research. This is not simply an exotic variant of consultation. Instead, it is active co-research, by and for those to be helped. Nor is it used by one group of people to get another group of people to do what is thought best for them. Rather, it is a genuinely democratic non-coercive process whereby those to be helped, determine the future of their own decisions.[85] Participatory research can help to:

- identify barriers which deter communities from using services;
- provide a better understanding of hypothesised barriers;
- facilitate greater understanding and awareness of a community's needs;
- develop relevant social skills among healthcare consumers and among health mediators and so reduce disparities in health outcomes;
- hold communities responsible for their own decisions by engaging them in defining and supporting the quality of services they want;
- enable providers to identify and recognise root causes of problems with their services.

Participatory meetings will help clinicians and other healthcare providers become more aware of supportive networks in the Panjabi community. These can be based around a neighbourhood, place of origin or, perhaps most importantly, marriage. Although such networks can be supportive, they may also be watchful and controlling.[86] An understanding of their local significance is critical to the development of a Punjabi patient-centred service. A potential example of such an approach is Apnee Sehat. This model of care aims to redesign patient care pathways, involving new partners for access such as pharmacists in the community. It will look to signpost high-risk individuals identified by healthcare providers in the community. Apnee Sehat aims to develop integrated healthcare models overcoming traditional barriers to specialist support for community services, while working closely with GPs and consultants. An example will be the development of one-stop shops for communities.[87]

Such one-stop shops will need to consider the approaches taken by the Panjabi community to the discussion of personal problems. It would appear that most Panjabis prefer to discuss such problems with someone of a similar age.[21] People were twice as likely to choose a neighbour of a similar age as their confidante than a son or daughter. That person was almost three times as likely to be a woman. When offered the opportunity to consult with a member of their own ethnic group who spoke their language, take up of services was much increased.[88] However, the patient is likely to take a family member to the consultation rather than a neighbour or friend.[21]

The Panjabi community in Britain is substantial. As yet clinicians, nurses, managers and self-help organisations in the field of gastroenterology have failed to provide adequately for their needs. This failure includes the recognition of increased frequency of certain diseases, diagnostic and therapeutic needs. The underlying problem is the inadequacy of communication and it needs to be improved. The use of local participatory meetings will allow the emergence of community-owned solutions.

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Affifa Farrukh **Saad Sayeed and John Mayberry**

Oral Health and the Provision of Care to Panjabi Patients in the UK

Abstract: There is a substantial Panjabi community in the UK and its language is the second most common to be used in the country. As a result, it is critical that all practitioners concerned with oral health are aware of the dental practices of this community and of the increased risk of conditions such as head and neck cancer. This review assesses work published in the UK as well as in India and Pakistan.
It emphasizes the need for a better understanding of cultural aspects of our care. Of course many aspects are not unique to this community but a better understanding will help with approaches to other communities. Social practices, such as paan use, can occur with greater frequencies amongst others, such as the Bangladeshi community. However, the purpose of this review is to concentrate attention on the largest minority community in the UK and, through this mechanism, to encourage interest in other groups. This interest should lead to practical approaches, such as: the development of relevant focus groups to improve clinical care; to develop outreach programmes to schools and community associations, including temples, gurdwaras and mosques; the production of appropriate literature and other media.

Clinical Relevance: This review should ensure that the reader is aware of attitudes towards dental care in the Panjabi community and of the increased frequency of a range of clinical conditions.

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The Panjabi community is the second largest in Britain with about 1.3 million members.[1] Its language continues to be the most common one after English spoken by school children and in some homes is the language of choice.[2] For many, access to healthcare is limited by both linguistic barriers and social deprivation.[3] The impact of these factors on health was well summarized by Caroline Wright when she wrote for the BBC:

'Although this is something often deemed controversial, poorer health outcomes, decreased comprehension of diagnoses and reduced satisfaction with care are all associated with limited English proficiency and cannot be ignored.[4]

The General Dental Council has expressed its views in *Standards for Dental Professionals:*

'Promote equal opportunities for all patients. Do not discriminate against patients or groups of patients because of their sex, age, race, ethnic origin, nationality, special needs or disability, sexuality, health, lifestyle, beliefs or any other irrelevant consideration.'[5]

and calls on practitioners to communicate:

'effectively with patients'[5]

It has not adopted the more rigorous comments of the General Medical Council which requires that practitioners:

'must make sure, wherever practical, that arrangements are made to meet patients' language and communication needs.'[6]

Oral health is no exception and the need for appropriate support urgent. This will only be effective if developed in conjunction with the community. An example is the *Smile with the Prophet* campaign (Bradford and Airedale PCT *Smile with the Prophet: Oral Health Programme*) through which young people develop an awareness of regular dental hygiene and this will contrast with the view of some older patients that the role of the dentist is to deal with acute pain or make dentures. In addition, appropriate education is needed to deal with oral tobacco and paan use, both of which are now readily available within the UK. Their use is clearly linked to the high prevalence of oral cancer in the Panjabi community.

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The Panjabi community in the UK

Panjabis first came to the UK in significant numbers as a result of taking part in World War I. However, the main migrations followed World War II and the division of Panjab between Pakistan and India. In the 1950s and later, there were significant migrations from East Africa, especially Uganda, Tanzania and Kenya. A later group came from Afghanistan and work and live around Southall.[6] The Muslim Panjabi community largely live in Birmingham, Bradford, Oldham and surrounding towns.[7] Sikhs are commonly found in Birmingham, Ealing (Southall), Sandwell, Hounslow, Wolverhampton, Coventry, Redbridge, Leicester, Hillingdon, and Slough (Figure 1).[8]

Social deprivation has been reported in a number of studies amongst Panjabis in the UK, as well as in other communities. This has included: long working days, low income, crowded housing, liability to attack and perceived lack of social support for women.[9,10]

As postulated by the Inverse Care Law, service utilization amongst people from socially deprived communities is often poor.[11] Furthermore, simply providing written information is inadequate. A study from the West Midlands has shown that fewer Panjabis can write English (41%) than speak it. Of those who can, only 63% consider their standard of written English to be good.[10] Any use of literature in Panjabi needs to recognize the different scripts used by Muslim and Sikh communities, as well as the existence of distinct languages, such as Saraiki. It should be tested on patients before general release to ensure adequacy of detail and presentation.[12]

In the long term, understanding of the nature and magnitude of ill-health amongst the Panjabi community may be improved through programmes such as '*Born in Bradford*'.[13] It promises to clarify the role of environmental, psychological and genetic factors on childhood development and subsequent adult health. It is based on a cohort of 10,000 women and their babies.

Awareness of oral health issues

In a comparative study from Amritsar of 100 Panjabi and 100 American children aged 11 to 16 years using a standardized WHO questionnaire, only 6% of those from Panjab considered the health of their teeth to be excellent. This compared with 28% of the Americans. Of the Indian children, 35% never visited a dentist. Fifteen per cent flossed regularly and 20% brushed their teeth less than once a week.[14] In a population-based study from Patiala, 16% of Panjabis believed that thread-like worms caused tooth decay and 57% believed tooth loss is a natural part of ageing.[15] Against such a background it is not surprising that 63% of women undergraduate students aged 16 to 21 in Panjab had caries.[16] The situation was exacerbated by the fact that 75% of those taking part in the study ate some form of junk food, including chocolate, candy and soft drinks, each day. The importance of the traditional Panjabi approach to oral and dental care is underlined by a study of 226 first and second generation Pakistani Muslim mothers living in Bradford. Dietary practices were similar and independent of educational background, linguistic ability and employment status. Children's snacks consisted of crisps, biscuits and sweetened milk or tea, and this was true for first and second generation mothers.[17] However, subsequent work has suggested parental views can be modified. Central to achieving such outcomes is the need to provide adequate language support and there is a clear preference for involvement of indigenous people as providers of the service.[18,19] The need for such educational programmes is emphasized by a study of five-year-old children in Dudley.[20] Dental caries was significantly more common amongst Asian children, once data were controlled for deprivation and fluoridation. This would reflect the findings of the British Association for the Study of Community Dentistry surveys which have repeatedly established a link between deprivation and childhood caries.[21]

Against this background within Panjab, only 20% use a datum or chewing stick.[15] In rural areas miswaks are used by 50% of the adult population, whereas in urban areas the majority use a toothbrush. Thirty six percent of the population clean their teeth on a daily basis, the remainder less frequently, with 8% never doing so.[22] The situation is complicated by the use of tobacco-containing mishiri as a tooth and gum powder. In addition, in Southampton less than 15% of South Asian adults over 55 years old attended a dentist on a regular basis. The rest saw a dentist's role as providing care when they had pain or needed new dentures.[23]


Figure 1. A typical supermarket store serving the South Asian community.

Use of tobacco products

In a study from schools in three Pakistani cities, 25% of pupils used some form of oral tobacco.[24] Its use is widespread in Pakistan and is associated with oral cancer. This makes up almost 12% of the tumour load amongst Panjabis, with one third of cases under 40 years old.[25] In the UK, it has been suggested that only 2% of Pakistani men regularly use oral tobacco, although the practice appears much commoner in older women.[26] One such product is a snuff known as *Naswar*. In an analysis of 30 brands in Pakistan, contamination with cadmium, lead, arsenic, chromium and nickel was common, with levels well above allowable limits, and this may account for its potential role as an oral carcinogen.[27] Such products can often be obtained in stores in the UK.

Smokeless tobacco use frequently starts before the age of 15 years with media advertisements responsible in 40% of cases and 31% responding to peer pressure.[28] Although favoured by people of Pashtun origin, its use is spreading. Between 2001 and 2006 the import of chewing tobacco and snuff into the UK saw an increase from 9000 to 19000 kg.[26] In 2012, 15 outlets in the London borough of Newham sold *Naswar* and users had again started at a young age and tended to have received limited education.[29] Indeed, in May 2011 *kHYBer nASWar BLACK SNUFF* was registered as a trademark in the UK by Basit UK Ltd (No 2571405).[30] This could be viewed as a positive step as 15% of such products are sold without relevant health warnings or adequate labelling.[31,32]

Use of paan

Paan is betel leaf on to which slaked lime is smeared and wrapped over a mixture of betel (or areca) nut and other additives such as tobacco, cardamom, aniseed, or gambeer (acacia catechu extract). It is chewed slowly and often kept in contact with the oral mucosa for several hours. The composition of nuts differs with methods of cultivation and preparation. Soaking and boiling, for instance, reduce the concentrations of tannins and alkaloids. Sliced and chewed betel nut allows direct and longer contact of the alkaloids with the buccal mucosa resulting in greater mucosal penetration.[33] Paan, supari, zarda, gutkha and paan masala are all readily available in the UK (Figure 2). The brightly coloured packaging and sweet flavours, including chocolate, suggest that they are targeted at young consumers.[32] In a Pakistani study of 370 students aged between 10 to 15 years, 85% were regular users of such products.[34] Indeed, studies from Panjab have found that products, such as paan, pasand candy and paan masala sachets are readily available outside schools.[35] In Tower Hamlets, of 700 school children, up to 92% were current users of some form of betel nut. The highest prevalence was for areca nut alone (36% boys, 43% girls), followed by mistee paan (35%, 29%), betel quid (27%, 26%) and paan masala (14%, 16%). Of current users, up to 13% used all four. Most pupils had started between ages 5 and 12 years. The frequency for each habit was between 3 and 5 episodes per week. However, boys used paan masala approximately 10 times per week.[36]

Prevalence of oral disease

Caries and periodontitis

In a cross-sectional study of 1000 people from Ludhiana, use of smokeless tobacco, such as khaini, quid, misri or zarda, was also associated with periodontal disease. In particular, smokers with coronary artery disease showed significant periodontal disease, including calculus and loss of tooth attachment.[37] Participants in the study who came from urban areas had significantly more advanced periodontal disease, with 23% showing loss of tooth attachment compared to 13% in rural residents.[38] The fact that these products are used by many young people in the UK would suggest that similar results will be seen in the UK over the coming decades.

Fluorosis

During the 1960s, 46,000 children were examined in 358 villages in Panjab. The incidence of dental mottling ranged from 23 to 81% in children and from 14% to 71% in adults.[39] This high incidence amongst Panjabis was first reported from Lahore by Day in 1940.[40] It is likely that this will be true for new Panjabi migrants to the UK.

Oral submucosal fibrosis

Oral submucosal fibrosis as a premalignant lesion has been clearly linked to the use of betel nut.[34] During recent years there has been a steady growth of oral tobacco and paan use in the UK. This has been associated with increased imports and more aggressive marketing of these products. As yet the expected increase in cases of oral submucosal fibrosis has not been seen. Case reports are appearing with more regularity and it seems probable that their numbers will continue to grow.[41]

Figure 2. Commonly available oral refreshers which contain betel nut.[1]

Product	Adjusted odds ratios
Chewing Tobacco	8.3
Mishiri	3.3
Gutkha	12.8
Supari	6.6
Bidi	4.1

Table 1. Risk of oral cancer related to tobacco and betel nut use. Modified from Madani, Dikshit and Bhaduri.[43]

Oral cancer

Between 1995 and 2002, the Karachi Cancer Registry recorded the highest incidence of cancer of the oral cavity in the world. Over the 8-year period there were 2253 cases, with 56% involving the buccal mucosa.[42] In 30% of cases, the patient was under 40, with this trend increasing during the time of the study. The poor and those with low literacy were most at risk. These developments have been linked to the increased use of oral tobacco and especially paan masala.

The risk of oral cancer related to tobacco and betel nut use is summarized in Table 1.

In her research, Yasmin Bhurgri drew attention to the importance of audio-visual educational material amongst any target population in view of this low literacy rate.[42] Within the UK and the West, in general, a similar sensitivity in the provision of educational material is needed. A recent case-controlled study from Pune Cancer Institute in India has confirmed the role of a range of tobacco and betel products in the genesis of oral cancer.[43]

Interventions

In a study of 210 Panjabis and 168 English patients drawn from five general practices in London, bilingual staff were favoured over translators.[44] The influence of communication and parental beliefs about health issues was investigated in a study from seven general practices in a multi-ethnic neighbourhood in Rotterdam, which included South Asians. Mutual understanding was often poor and led to poor adherence to prescribed therapy.[45] Such findings emphasize the need to adopt a more structured community-based approach than that suggested by the British Dental Association in an Occasional Paper on Oral Screening, which was published in 2000:

- Team members need to be sensitive to cultural differences of this sort;
- Practice meetings could be used for sharing experiences and understandings.

Other health workers dealing with minority ethnic communities will be able to give supporting advice. Generally, people from minority ethnic groups have distinct health problems – more diseases and poorer access to services. Problems can be especially acute for women. Health authorities use 'linkworkers' and patients' advocates in some areas to help people access healthcare.[46]

A successful approach requires close collaboration between the community and the providers of healthcare. The needs of the community must be addressed and, to ensure success, the community must be involved at all stages of the programme. This means that health carers must be open and prepared for a different approach to the one they envisaged. In British Columbia, focus groups from the Panjabi community informed the design and size of posters aimed at reducing early childhood caries.[47] Any new model for the care of Panjabi patients needs to bridge the gap between provider opinion and users' perceptions of the service. The best prospect for achieving this outcome is likely to be through the use of participatory meetings and research.[3] This is a genuinely democratic non-coercive process whereby those to be helped determine the future of their own decisions.[48] Participatory research can help:

- Identify barriers which deter communities;
- Facilitate greater understanding and awareness of a community's needs;
- Develop relevant social skills amongst healthcare consumers and amongst health mediators and so reduce disparities in health outcomes;
- Hold communities responsible for their own decisions by engaging them in defining and supporting the quality of services they want;
- Providers identify and recognize root causes of problems with their services.

Participatory meetings as described, whose principles have parallels with the Alma Ata Declaration,[49] will help clinicians and other healthcare providers become more aware of supportive networks in the Panjabi community. These can be based around a neighbourhood, place of origin or, perhaps most importantly, marriage. Although such networks can be supportive, they may also be watchful and controlling.[50] An understanding of their local significance is critical to the development of a Panjabi patient-centred service. Its principles can be used with any minority community.

One of the few examples of a successful approach using these techniques was *Smile with the Prophet*. This was an oral health programme in Bradford and Airedale which attempted to link toothbrushing and other aspects with ritual and cultural aspects of hygiene. It was based around mosques and madrassas and was supported by *Race for Health*[51] and approved by the Council for Mosques.[52] It encouraged youngsters to brush their teeth daily through linking this with the teachings of the Prophet and Islam. The teaching plan had six sessions which developed oral health messages and how they fitted in with Islamic teachings, such as cleaning your teeth before prayer and not eating or drinking to excess. Pupils were given an activity book containing puzzles, drawings and a toothbrush and toothpaste.[53,54] Amongst the concepts promoted by the leaflet are the following extracts:

'Just like the Prophet I will also
- Eat only the purest of food
- Drink milk and water

In your honour I will keep my teeth healthy by
- Choosing healthy snacks between meals
- Keep sugary foods and drinks to mealtimes only

With strong healthy teeth I can
- Eat and enjoy the fruit you provide
- Speak to you in prayer
- Show you the charity of my smile'[55]

With the support of the local Council for Mosques the programme has also been introduced in Oldham.[56] The effectiveness and general acceptability of this programme is yet to be fully assessed.

The involvement of local religious leaders, community radios and mosques, temples and gurdwaras in health campaigns is becoming more widespread. For example, the distribution of free miswaks linked to a 'Stop smoking' campaign during Ramadan in 2012 was received enthusiastically by the community in Leicester. The use of community partners and networks gave the campaign an effective edge, although it again awaits formal assessment.[57]

There are no comparable programmes directed at Hindu or Sikh Panjabi communities.

Conclusion

The Panjabi community in Britain is substantial. As yet clinicians, nurses, managers and self-help organizations in the field of oral health have failed to address the needs of Panjabi patients adequately. This includes recognition of increased frequency of certain diseases, diagnostic and therapeutic needs, as well as the role of social habits. The underlying problem is the inadequacy of communication and the answer needs to be centred around its improvement. The use of local participatory meetings will allow the emergence of community owned solutions as opposed to imposed external directives.

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REVIEW ARTICLE

Inflammatory bowel disease and the South Asian diaspora

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Key words
diaspora, inflammatory bowel disease, South Asian.

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Abstract

Migration is associated with changes in the incidence of diseases, often linked to new environmental exposures or movement away from such exposures. Studies are complicated by the time and length of migration and also by differences in the experience of second- and third-generation migrants. South Asian people have migrated across the world. In this review, the incidence and prevalence of inflammatory bowel disease in these communities is considered, along with their potential role in future investigative studies of the diseases' etiology.

Introduction

The migration of peoples has been classically associated with changes in the nature of the diseases they experience. In general, communities have moved away from the diseases they experienced in their country of origin and toward the diseases of their adopted country. Over the years, there have been many descriptive epidemiological studies that have documented examples. Indeed, migrant studies only provide useful information when there is a difference in risk between the host country and the country of origin. The interpretation of such studies can be complicated when there has been a steady inward migration over many years, so the migrant population has been exposed to potential etiological factors for different periods. In such cases, there can be an advantage in comparing first- and second-generation populations, where the populations are genetically similar, in contrast to the host population. (Godfrey *et al.*, Parkin *et al.*).

Migration may be considered a large-scale natural experiment that can include the effects of urbanization and community changes in diet. A limitation, however, is that migrant communities are nonrandom samples of the population in the country of origin.[24] Those pull-and-push factors that led to migration distinguish migrants from their contemporaries who remained at home. Education, professional skills, and poverty can all play a part and ideally need to be taken into account as potential confounding factors. In addition, once in the host country, migrants are rarely distributed homogenously but rather tend to settle in certain areas, often urban in character, thus establishing what may be considered a "colony" to which later migrants are drawn.[12]

South Asians and their history of migration

The movement of South Asian people from the Indian subcontinent in the 18th and 19th centuries took them to East and South Africa, Malaysia and Singapore, Fiji, and the Caribbean. They were often neither willing migrants nor had any hope of return to the Indian subcontinent. In the 20th century, migration to the United States, Canada, Australia, and Israel became frequent destinations for migrants, with economic factors and religion being significant pull factors.[27]

In Malaysia, Singapore, Fiji, Trinidad and Tobago, South Africa, Canada, and the United Kingdom, the populations of South Asian migrants have been sufficiently large to allow meaningful studies of prevalence and incidence (Table 1). The factors that led to the migration to these countries were significantly different and drew on various sectors of the South Asian community. In Fiji, South Asians arrived as indentured laborers between 1903 and 1916 in order to work on the sugar cane plantations. Most came from Uttar Pradesh, West Bengal, and Bihar. Since the coup of 1987, about one third of the South Asian population has emigrated to the United States, Canada, and Australia. This amounts to about 100 000 people. People from Bihar were also taken to Trinidad and Tobago as indentured labor to work on the sugar plantations and now compose almost half of the population, amounting to half a million people. Comparable data on incidence and prevalence are not available for South Asian people living in these areas, but both inflammatory bowel diseases are significantly more common in the migrant than in the indigenous population.[10,11,25] The modern South African Indian community is also largely descended from indentured laborers who worked on the sugar plantations of Natal. Many came from southern India.

In the United Kingdom, there has been a sequence of push-and-pull factors that have drawn South Asians. In the 19th century, education, work as servants, and the merchant navy all played a part. In World War 1, South Asian troops fought on the western front and convalesced in the south of England. However,

Table 1 Studies of incidence and prevalence of inflammatory bowel disease in the South Asian diaspora

Country	Study period	Percentage of population (%)	Incidence	Prevalence	Hospital prevalence	Ratio to indigenous community
North Punjab, India UC [29]	1999–2000		6	44.3		
Malaysia [30]	1985–1998	7.3	0		17.9	4.89
Singapore [8]	2000	9.7		16.2		2.7
Fiji [20]	1985–1986	44	1.7			11
Trinidad and Tobago [1]	1968–1978	40.3		93		23
Durban, South Africa [26]	1983–1987	2.6	2.7			
United Kingdom [28]		2				
Scotland [2]	2000–2009					UC 1.7 Crohn's 2.0
Tower Hamlets						
UC [7]	1972–1989		1.8			0.29
[31]	1997–2001		8.2			
CD [22]	1972–1989		2.3	33.2		0.56
[31]	1997–2001		7.3			
Leicester						
UC [21,23]	1981–1989		13.9	135		1.5–1.8
[3]	1991–1994					2.5
CD [6]	1981–1989		3.1			0.66
Canada		2.8				
Children in British Columbia [17]	1985–2005					
UC			6.7			7
CD			6.4			1.6

a major push factor was the expulsion of South Asians from Uganda by Idi Amin as well as their leaving Malawi, Kenya, and Tanzania. The resulting distribution of South Asian communities around the United Kingdom has meant that most of the Asian community in Leicester is of Gujarati or Punjabi origin, whilst in Tower Hamlets, the community is largely of Bangladeshi origin.

The majority of Indian Jews migrated to Israel after 1948. Most settled in agricultural settlements or in the area of Beersheba. However, despite there being a significant number of epidemiological studies from this area, none have focused on the Indian community, which has largely been subsumed amongst those "born in Asia." However, the concept of studying disease incidence amongst Indian Jews has been raised by Odes *et al.*[14] in a study of esophageal cancer.

South Asians and inflammatory bowel disease

To date, there have been studies on the incidence and prevalence of inflammatory bowel disease amongst South Asian communities in Canada, the United Kingdom, West Indies, South Africa, Fiji, Singapore, and Malaysia. (Table 1) A major limitation is that, although comparisons can be made with the indigenous populations of those countries, there is only one study from Punjab in the north of India, and this was almost 20 years ago. A further limitation is that there have been few sequential studies assessing how incidence has changed. The only study concerning both ulcerative colitis and Crohn's disease, covering a 30-year period where the same methods of case identification and definition were used, was in Tower Hamlets. During this period, the frequency of the diseases increased between three- and fourfold. A study from Leicester demonstrated that the severity of the disease was significantly worse in the second generation compared with the first generation or with the indigenous population. Whether such differences are linked to changes in diet and social habits, such as the chewing of betel nut, remain open to discussion.[9] At the time of the study which suggested that chewing betel nut might confer benefits comparable to smoking in ulcerative colitis, there was some evidence that its use was on the decline, especially in the Bangladeshi community of East London. Nevertheless, 77% of young people had engaged in the habit, and between 54 and 92% of these people remained current users.[4,13,18] With effective education programs aimed at reducing the frequency of betel nut use, any protective effect it may have had will disappear, and it is likely that the frequency and severity of inflammatory bowel disease in second- and third-generation South Asians will dramatically increase. It is of some interest that such changes have already been seen in diabetes and cardiovascular disease.

The incidences of ulcerative colitis in Tower Hamlets and Fiji during similar periods are comparable amongst South Asian communities of similar origins. In contrast, ulcerative colitis was much more common amongst the indigenous population of Tower Hamlets than it was in Fiji. The incidence of ulcerative colitis amongst South Asians only started to move toward that of the indigenous community after they had lived in London for 25 years. Support for such a lag period also comes from the study of first- and second-generation migrants in Leicester. Clearly, in areas such as Canada, Australia, New Zealand, and the United States, where South Asian migration is relatively recent, it is unlikely that dramatic changes in incidence will be seen for a quarter of a century.[10,11] The situation, however, is complicated by migration from areas of high incidence, such as the United Kingdom, and the changes may appear in a much shorter period.

One study that considered the diet of South Asian patients with inflammatory bowel disease would suggest that they have adopted the lifestyle of the community in which they live.[20] Again, as with diabetes and cardiovascular disease, such dietary changes may themselves be important etiological factors but also reflect a more widespread change in lifestyle.

The future of migrant studies

With the dispersal of South Asian people across the world, the only approach to investigating incidence and etiological factors in the diaspora would be through a central organization. For example, with the existence of Shree Ramkabir Bhakta Samaj and its publication of directories of members of the Bhakta family in the United States, Canada, Australia, New Zealand, the United Kingdom, Zambia, and Panama, this becomes a possibility. Perhaps the most important factor is the existence of a directory for Bhaktas living in India, largely in Gujarat. Central directories have already proven to be valuable in studies of inflammatory bowel disease where work on Mormons confirmed the role of nonsmoking as a risk factor for ulcerative colitis.[16] Work amongst South Asian migrant communities may provide clues to understanding why inflammatory bowel disease has become so common over the last 40 years.

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gastrointestinal disorders

MDPI

Review

Evidence of Differences and Discrimination in the Delivery of Care: Colorectal Screening in Healthy People and in the Care and Surveillance of Patients with Inflammatory Bowel Disease

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Abstract: Objectives: In this review the management of colorectal disease will be investigated as an exemplar of common practice in the UK in an attempt to identify factors responsible for the more general experiences of patients from ethnic minorities. Within this field such populations have a lower uptake of cancer screening programmes and their experience of day-to-day care for chronic gastrointestinal disorders is poor. Study design: PubMed and Google Scholar were reviewed in 2016 to identify publications concerning colorectal screening in patients with inflammatory bowel disease and healthy communities. Methods: Data were extracted from each paper and the references exploded to identify other potential reports. Results: It is reported that barriers exist both at individual and access levels but little has been done to overcome these. There have been a number of suggestions as to how to provide equitable access, but there is a clear need to ensure that these are evidence based and have been tested and shown to be effective in clinical trials. Conclusions: Clearly, current systems of surveillance and screening will only make a difference if they provide effective and acceptable services to all potential clients. Most programmes fail to address the specific risks and anxieties of minority groups, which are thought to be poorly compliant. This review considers those factors that may play a part and suggests approaches that could overcome these deficiencies. Some clues as to these factors may come from work with patients with chronic disorders.

Keywords: surveillance; screening; colon; inflammatory bowel disease; ethnicity; chronic disease

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1. Introduction

The delivery of care should be equitable and free of discrimination. However, ethnic minorities still experience institutional racism with evidence of a range of disparities in the delivery of healthcare across many specialties. In the UK, such differences are currently being reported in mental health [1], diabetes and coronary artery disease [2], oesophageal and gastric cancers [3], as well as hip and knee replacement [4]. In this review the management of colorectal disease will be investigated as an exemplar of common practice in an attempt to identify factors responsible for such experiences. Within this field ethnic minority populations have a lower uptake of cancer screening programmes in the UK [5–7]. It is reported that barriers exist both at individual and access levels but little has been done to overcome these. Sociodemographic factors cannot fully explain the suboptimal participation by ethnic minority groups and further research is essential, especially as some dispute the existence of such disparities in care. This is despite the findings of studies, as in Leeds, where nurses were found to have limited understanding of the local Pakistani community and were ill-prepared to deal with their needs with associated evidence of racist attitudes [8].

Disparities in healthcare access affecting ethnic minority and "hard to reach" groups present a complex challenge to clinicians, managers and policy-makers. There have been suggestions as to how to provide equitable access, but there is a clear need to ensure that these are evidence based and have been tested and shown to be effective in clinical trials [9,10].

There is a growing movement across the world to introduce screening programs for the early detection of colon cancer or precancerous states, but unfortunately the literature on various cancer screening programmes persistently shows lower uptake especially by ethnic minorities [11–25]. A study from almost 20 years ago showed that the incidence of colorectal cancer amongst south Asian migrants to the UK was increasing [26]. However, little has been done in spite of this constant and consistent message to improve the situation. Published research on interventions to improve screening uptake in such groups is rare and suggests that the demand for effective approaches to rectify these barriers to cancer screening programmes needs further evaluation. In particular, most programmes fail to address the specific risks and anxieties of minority groups, which are thought to be poorly compliant. However, studies from China [27] and India [28] have shown the indigenous populations to be at comparable risk of cancer in ulcerative colitis and there are no reasons to believe that the situation would be any different for migrant communities from these areas. Despite these observations there has been little work on the impact of diversity on the care of patients with polyposis syndromes and long-term ulcerative colitis, and there is little evidence that funding bodies have plans to encourage research into interventions which would change this situation [29,30]. In these conditions, which are known to predispose to colorectal cancer, do patients have equal access to surveillance and so benefit from early detection of dysplasia or cancer? In the case of ulcerative colitis, can quality of care be assessed by examining whether people from diverse backgrounds experience similar approaches to monitoring the effect of aminosalicylate (5ASA) compounds on renal function or have comparable access to expensive treatments such as biologics and ileoanal anastomotic surgery? Such questions should underpin all aspects of research on quality of care and, at a time when we are all encouraged to be involved in "Quality Improvement Projects", this is an area of obvious need.

2. Review of Published Work

Study Design

PubMed and Google Scholar were reviewed in 2016 to identify publications concerning colorectal screening in patients with inflammatory bowel disease and healthy communities.

Review

There is recent evidence that patients from ethnic minority groups demonstrate significant differences in access to cancer screening as well as uptake of the services. Breast and cervical cancer screening are well established in the UK, but figures consistently show a lower uptake by ethnic minority groups, especially South Asians. Although uptake in the Afro-Caribbean population has been reported to be equal to the white population, little is known about communities such as the Chinese [9,10]. In a MORI survey in primary care in 1995, Carr-Hill and Rudat [9] reported a relatively high uptake of cervical screening by Afro-Caribbean people (87%), but a much lower uptake by South Asian women (70% Indian; 54% Pakistani; and 40% Bangladeshi). However, there are aspects which limit the applicability of these findings to colorectal cancer (CRC) screening. Firstly, breast and cervical screening programmes in the UK differ in organisation and delivery. Secondly, both programmes exclude men and so provide no evidence on how men would respond to CRC screening. Work in the UK on mass screening of healthy people by flexible sigmoidoscopy found that although intentions were comparable across various cultural groups, attendance was considerably lower among Asians (54%) compared with White (69%) or Black (80%) respondents [6]. International literature, mainly from USA, does provide evidence of lower uptakes of faecal occult blood testing (FOBT), flexible sigmoidoscopy and colonoscopy amongst minority ethnic populations [11,12]. The UK CRC screening pilot programme amongst the general population reported an overall uptake of 62% for faecal occult blood testing (FOBT) for English people. This was considered acceptable, but uptake was poor in the South Asian community, with figures for Muslims as low as 32%. The highest figure amongst South Asians was for Hindus, but was still only 44%. Unfortunately, analysis of FOBT uptake rates in this study was dependent on surname recognition software and so was unable to distinguish Afro-Caribbeans from English people [5]. In a subsequent analysis of the first 2.6 million people to take part in the national screening program in the UK, the most ethnically diverse areas had the lowest uptake (38%), compared to other communities where the figure was between 52 and 58%. These differences were independent of social, economic and personal status. However, ethnic disparities were more pronounced in men but equivalent across age groups [6,7].

Where studies have examined sociodemographic factors [5,9], it is commonly reported that these cannot fully explain such variations. In the general population the uptake of FOBT screening remains two and a half times lower amongst Muslims and Sikhs and about twice as low amongst Hindus. Colonoscopy uptake rates were also significantly lower amongst Asians (55%) compared with 74% for non-Asians [5]. However, there has been no work on uptake rates amongst patients with chronic gastrointestinal diseases, such as ulcerative colitis. Indeed there has been little work on any aspect of healthcare amongst this group of patients and the impact of diversity issues, such as age, gender, ethnicity, ability and sexuality. In the one report on long-term care of patients with ulcerative colitis, patients of South Asian origin clearly had a poorer experience than English patients in the same community. For example, although the difference did not reach statistical significance, only 32% of South Asian patients underwent surveillance colonoscopy compared to 43% of English patients.

A study from the USA suggested that low uptake of screening for colorectal cancer in the general population may be due to a lack of awareness and inadequate provider counselling rather than a poor acceptance of the scheme [11–13]. To encourage participation and improve compliance, physician recommendation was suggested to have a major impact [14–18]. The problems generated by developing schemes with an English language basis and failing to address cultural issues are well established in many studies. Undoubtedly such an approach is likely to strengthen perceived discrimination, as has been demonstrated amongst American Muslim women in breast cancer screening programs. Language issues are clearly of major significance. An American study has shown that bilingual immigrants are better able to negotiate the healthcare system than those fluent in English or their native language alone [20]. African migrants in Guangzhou, China found the language barrier to effective healthcare a major issue and this led to a distortion in the patient–doctor relationship. Doctors were seen to be too hurried and to lack cultural awareness [21]. Such findings are important because it is generally agreed that poorly educated people are less likely to receive counselling about CRC screening from their health provider. Individual knowledge of colon cancer, lack of perception of illness in the absence of symptoms [19,22,31], health literacy [22–25] and fear of further investigations also deter participation. Lack of awareness is globally accepted as a proxy for lower compliance. However, a study from Leicester on CRC screening in a workplace setting reported that the lowest uptake of FOBT was amongst doctors and managers (26%) when compared with clinical support staff (56%). This difference was not further explored, but emphasises the fact that knowledge of CRC, its early detection, prevention and management are not necessarily linked to high uptake rates in screening programs [31].

In polyposis syndromes there is evidence that the stigma associated with cancer or family risk play an important role in preventing South Asian people seeking genetic counselling and associated preventive screening [29]. Significant differences regarding attitude towards disease and its impact on daily life are also found amongst ethnic groups with inflammatory bowel disease (IBD) [30]. We know that, in general, adherence to screening programs amongst people with ulcerative colitis is low (Table 1), but little is known of the reasons for this noncompliance [32–35]. In the case of patients from ethnic minorities we have to question the role of senior medical personnel in ensuring they receive appropriate explanations about the disease, appropriate support and community education. Clearly there is evidence that some clinicians shy away from dealing with patients from a different community to their own [36].

Table 1. Adherence/participation rates in surveillance programs in ulcerative colitis.

Country	Study Design	Year	Total Patients	Non Compliant
Sweden [35]	Prospective	1977–2002	211	36/211 (17%)
Sweden [34]	Prospective	1977–1991	131	13/131 (10%)
Italy [32]	Prospective	1980–2000	65	29/65 (45%)
Italy [33]	Prospective	1989–1992	65	15/65 (23%)

There is growing evidence of significant differences in many aspects of the care of patients with gastrointestinal diseases from minority communities. In North Manchester, Redbridge and Leicester the number of South Asian patients who received biologic treatment for Crohn's disease was significantly less than British/White patients [37]. In a recent UK nationwide review of colectomies for ulcerative colitis, Indians had a significantly higher rate than White Europeans (11 vs. 7%. In contrast, Pakistanis had a similar (7.0%) and Bangladeshis a significantly lower (4.7%) colectomy rate [38]. Twenty years ago there was evidence that the disease may have been milder in the South Asian community [39]. In addition there was significant concern about the possibility of a stoma amongst South Asian patients [40]. Although within a generation disease severity was comparable between South Asian and White patients in Leicester [41], the recent study of a higher rate of colectomy amongst Indian patients raises serious questions about their access to effective alternative expensive medical treatments. With the increased availability of biologics for management of the condition, the observation that access to such therapy is not equitable in the UK emphasises the need for clinicians to urgently address these issues. For those who doubt the reality of such differences in care there is added confirmation from the USA. In both Atlanta and Baltimore, White patients were significantly more likely to receive infliximab, while in Miami, the ratio for Hispanics was 22% compared with 56% for White-Americans [42–44].

3. Discussion

In the 2011 Census, Black and ethnic minorities constituted almost 11% (6.2 million) of the population in the UK. South Asians accounted for about half this population. There are also 1.15 million Afro-Caribbean people in the UK. These groups are younger than the White population, which means that the ethnic minority percentage of the population is likely to grow in coming years [45]. Following the implementation of the Race Relation Amendment Act 2000, it is a statutory duty on all NHS agencies to "have due regards to the need to eliminate unlawful discrimination" and maintain racial equality. Access to care is a product of the interaction between provider services, users and planners. Quality of care is defined in terms of client centred services, meeting needs and expectations. It is an ongoing process that incorporates clients' rights and their satisfaction with the system. It entails access to accurate, appropriate, understandable and unambiguous information at convenient times with no physical barriers. It helps clients make a well-judged decision based upon information, understanding and options, i.e., informed choice rather than coercion.

Provider performance is the building block of accountability in a system, which is meant to offer a sustainable and continuous flow of services to satisfy its clients which in turn is measured by their level of participation. This collective vision of quality woven together from individual voices from different communities can give systems, such as screening and surveillance, a new life, where individuals are no more just patients, but rather, healthcare consumers. It not only holds clients responsible for their decisions by engaging them in defining and supporting the quality of services they want, but also helps providers identify and recognise root causes of problems with their services. However, as Diangelo recently pointed out, "if I am not aware of the barriers you face, then I won't see them, much less be motivated to remove them" [46]. There is more needed than simple education. Although education can improve healthcare workers knowledge of minority communities there is no evidence that it will change clinical practice [47]. The work of van Ryn et al. has shown that where clinicians have an awareness of the issue and are prepared and able to address institutional racism in their delivery of care, then such individuals will be able to make changes in their own practices and also that of their institutions [48].

It is clearly necessary to broaden access so as to ensure "equitable" care in this vision of the health industry in UK. Traditionally access has been measured in terms of utilisation and this is based on "Demand" and "Supply" concepts. This system is now complicated by the fact that we can identify those who do or do not use its services but are unable to explain why the benefits experienced by one community are not utilised by others. Though the norms of provider behaviour will determine what is deemed accessible by users, the decision to seek formal care will be influenced by how the services on offer are perceived by potential users. Healthcare is a complex system where every participant interacts with each other in a dynamic way, where changes in one element can alter the context of all others as well as subsequently being influenced by them. It involves individuals making discrete choices based on their own assessment of options. These decisions are often a result of formal or informal negotiations between multiple members of the community, rather than simply an individual weighing up different courses of action. However, there are only limited data on how this plays out in practice for people with chronic gastrointestinal diseases, such as ulcerative colitis. So, if the healthcare system is meant to be client oriented, it has to take into consideration what is important to its consumers so as to ensure the ongoing trust of existing users and their recommendation of it to others. For example a persistently lower uptake of cancer screening by South Asians reflects the fact that cancer screening services in the UK are not sensitive to the needs of ethnic minorities. Barriers exist for both individuals and at access levels including cultural differences, conscious or unconscious racial bias, professional and cultural insensitivities, language and literacy, stress from experiences of discrimination and unmeasured socioeconomic variables. All are intertwined and can create a distrust of healthcare services. Unfortunately little has been done to introduce and evaluate the effectiveness of implementations once such barriers are identified.

The purpose of this review is to expose the existence of barriers to care amongst patients with chronic gastrointestinal disorders such as inflammatory bowel disease and their link to diversity. Its secondary purpose is to assess the magnitude of these disparities. There is a clear need for a more formal investigation through qualitative techniques of the reasons behind these barriers. Such qualitative techniques must involve and, ultimately, be led by truly representative members of those groups whose access to quality care has been impaired. It cannot depend on token members, acceptable to a majority of the healthcare providers, and representative of no one. However, before gastroenterologists can engage with the communities they serve they need, on an individual basis, to assess whether their service truly delivers care regardless of ethnicity, religion, gender, sexuality or ability. For example, how many of us have engaged with the signing community, although there are an estimated 125,000 users of British Sign Language according to a recent general practice poll [49]? Some basic practical tests we can all apply include

1. Does my clinic composition represent the community in which I work?
2. Do I personally ensure that I see an appropriate cross-section and make use of professional translation services?
3. Am I properly and correctly informed about the cultural background of my patients?

As gastroenterologists we need to develop formal links with minority communities, encourage them to set up patient groups and, through formal techniques, such as the Delphi Method, start to identify ways of removing barriers of access to care and ensure that the care we do deliver is equitable and fit for purpose.

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