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).

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).
**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.

| Trust and Trust Type | White British | White Irish | White Other | White | Afro-Caribbean | Asian |
|----------------------|---------------|-------------|-------------|-------|----------------|-------|
| **Wye Valley NHS Trust** |                |             |             |       |                |       |
| In-Patient Admissions | Population 172,000 | 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 | 22,000 | 360,000 | 19,000 |       |
| 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. | <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 | 1 |       |                |       |
| Proportion Statistic | 1.6 | 0.8 |       |       |                |       |
| Significance | n.s. | n.s. |       |       |                |       |
| **Croydon Health Services NHS Trust** |                |             |             |       |                |       |
| In-Patient Admissions | Population 172,000 | 5400 | 2300 | 180,000 | 60,500 |       |
| Cases of IBD | 1475 | 63 | 20 | 573 | 69 |       |
| Expected cases of IBD | 1475 | 46 | 11 | 61.4 | 46 |       |
| Proportion Statistic | n.s. | 0.0001 |       |       |                |       |
| Significance | p < 0.0001 |       |       |       |                |       |
| **Nottingham University Hospitals NHS Trust** |                |             |             |       |                |       |
| In-Patient Admissions | Population 276,000 | 14,100 | 5133 | 52 |                |       |
| Cases of IBD | 5133 | 262 | 9.4 |       |                |       |
| Expected Cases of IBD | 5133 | 262 | 9.4 |       |                |       |
| Proportion Statistic | n.s. | 0.0001 |       |       |                |       |
| Significance | p < 0.00001 |       |       |       |                |       |
| **University Hospitals of Derby and Burton NHS Foundation Trust** |                |             |             |       |                |       |
| In-Patient Admissions | Population 377,000 | 14,100 | 52 | 220 |                |       |
| Cases of IBD | 52 | 12 | 6 |       |                |       |
| Expected Cases of IBD | 52 | 12 | 6 |       |                |       |
| Proportion Statistic | n.s. | 0.00001 |       |       |                |       |
| Significance | p < 0.00001 |       |       |       |                |       |
| **University Hospitals of Birmingham NHS Foundation Trust** |                |             |             |       |                |       |
| Use of Biologics | Population 622,000 | 14,100 | 52 | 220 |                |       |
| Cases of IBD | 94 | 6 | 6 |       |                |       |
| Expected cases of IBD | 94 | 12 | 6 |       |                |       |
| Proportion statistic | 1.4 | 1.4 |       |       |                |       |
| Significance | n.s. |       |       |       |                |       |
| **Kings College Hospital NHS Foundation Trust** |                |             |             |       |                |       |
| In-Patient Admissions | Population 170,000 | 14,100 | 52 | 220 |                |       |
| Cases of IBD | 13,003 | 2357 | 6004 | 236 | 236 |       |
| Expected cases of IBD | 13,003 | 2357 | 6004 | 236 | 236 |       |
| Proportion Statistic | 42.3 | 42.3 |       |       |                |       |
| Significance | p < 0.00001 |       |       |       |                |       |
| **NorthWest Anglia NHS Foundation Trust** |                |             |             |       |                |       |
| In-Patient Admissions | Population 159,000 | 14,100 | 52 | 220 |                |       |
| Cases of IBD | 8161 | 39 | 305 | 924 | 924 |       |
| Expected cases of IBD | 8161 | 39 | 305 | 924 | 924 |       |
| Proportion statistic | 23.6 | 23.6 |       |       |                |       |
| Significance | p < 0.00001 | p < 0.00001 | p < 0.00001 | p < 0.00001 | p < 0.00001 | p < 0.00001 |
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 FOI 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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