

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. ($\chi^2=9.56$, $P<0.05$). 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 ($\chi^2=7.59$, $P<0.05$). If the minimum number of admissions of 736 was considered, then $\chi^2=15.77$, $P<0.001$. 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 6% 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 2.0/10⁵ 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/aoc-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 ($\chi^2=9.56$, 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 $\chi^2=7.59$, with a sample size of 865, two degrees of freedom ($P<0.05$). If the minimum number of admissions of 736 is considered, then $\chi^2=15.77$, 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	White British	South Asian					
											White British				
Leicester	71	14	256	39	146	11	0	0	0	0	0	537	5.76	2	NS
Wolverhampton	21	4	26	5	6	0	0	0	0	0	0	62	0.0002	1	NS
Luton	2	1	137	16	18	0	0	0	0	0	0	174	1.59	1	NS
Sandwell & West Birmingham	7	1	13	16	2	0	0	1	0	0	0	40	4.6	1	<0.05
Birmingham	51	7	54	8	4	2	8	4	4	4	4	138	5.28	3	NS
Bradford	31	14	140	14	33	11	3	3	1	1	1	247	15.85	3	<0.001
Total	183	41	626	98	209	24	12	12	5	5	5	1,198	9.56	3	<0.05

$\chi^2=9.56$, 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 $\chi^2=7.59$, with a sample size of 865, two degrees of freedom and $P<0.05$. For minimum number of cases $\chi^2=15.77$, 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 Heller's 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 ($\chi^2=47.9$, with a sample size of 420, two degrees of freedom $P<0.001$) and White British patients ($\chi^2=208$, 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 1.0/10⁵ 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 2.5 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 Heller's 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 intermediaries 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 2/10⁵ 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

Reporting Checklist: The authors have completed the MDAR checklist. Available at <http://dx.doi.org/10.21037/aoe-20-72>

Conflicts of Interest: Both authors have completed the ICMJE uniform disclosure form (available at <http://dx.doi.org/10.21037/aoe-20-72>). The authors have no conflicts of interest to declare.

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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References

1. Mayberry JF, Rhodes J. Achalasia in the City of Cardiff from 1926 to 1977. *Digestion* 1980;20:248-52.
2. Mayberry JF, Atkinson M. Studies of incidence and prevalence of Achalasia in the Nottingham area. *Q J Med* 1985;56:451-6.
3. Mayberry JF, Atkinson M. Variations of the prevalence of achalasia in Great Britain and Ireland: An epidemiological study based on hospital admissions. *Q J Med* 1987;62:67-74.

4. Howard PJ, Maher L, Pryde A, et al. Five year prospective study of the incidence, clinical features, and diagnosis of achalasia in Edinburgh. *Gut* 1992;33:1011-15.
5. Farrukh A, DeCaestecker J, Mayberry JF. An epidemiological study of achalasia among the South Asian population of Leicester, 1986-2005. *Dysphagia* 2008;23:161-4.
6. Harvey PR, Thomas T, Chandan JS, et al. Incidence, morbidity and mortality of patients with achalasia in England: findings from a study of nationwide hospital and primary care data. *Gut* 2019;68:790-5.
7. Visram R. *Asians in Britain: 400 Years of History*. 2nd edition. London: Pluto Press, 2004.
8. Farrukh A, Mayberry J. Ethnic variations in the provision of biologic therapy for Crohn's Disease: A Freedom of Information Study. *Med Leg J* 2015;83:104-8.
9. Farrukh A, Mayberry JF. Patients with ulcerative colitis from diverse populations: the Leicester Experience. *Med Leg J* 2016;84:31-5.
10. Szczepura A. Colorectal Cancer Screening Pilot Final Report. Revised July 2003. Available online: <http://wrap.warwick.ac.uk/133/>
11. Farrukh A, Mayberry JF. 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. *Gastrointest Disord (Basel)* 2020;2:141-51.
12. Jack RH, Davies EA, Møller H. Breast cancer incidence, stage, treatment and survival in ethnic groups in South East England. *Br J Cancer* 2009;100:545-50.
13. Lear JT, Lawrence IG, Pohl JEF, et al. Myocardial infarction and thrombolysis: A comparison of the Indian and European populations on a coronary care unit. *J R Coll Physicians Lond* 1994;28:143-7.
14. Harrison EM, Docherty AB, Barr B, et al. Ethnicity and outcomes from COVID-19: The ISARIC-CCP-UK prospective observational cohort study of hospitalised patients. *THELANCET-D-20-12331* 2020. Available online: https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3618215
15. Shaligram A, Unirevi J, Simorov A, et al. How does the robot affect outcomes? A retrospective review of open, laparoscopic and robotic Heller myotomy for achalasia. *Surg Endosc* 2012;26:1047-50.
16. Oude Nijhuis RAB, Zaninotto G, Roman S, et al. European Guidelines on achalasia -UEG and ESNM recommendations. *United European Gastroenterol J* 2020;8:33-4.
17. El Kafsi J, Foliaki A, Dehn TCB, et al. Management of achalasia, do we need new guidelines? *Ann Med Surg (Lond)* 2016;12:32-6.
18. Andolfi C, Fisichella PM. Meta-analysis of clinical outcome after treatment for achalasia based on manometric subtypes. *Br J Surg* 2019;106:332-41.
19. Harvey PR, Coupland B, Mytton J, et al. The results of endoscopic and surgical treatment for achalasia in England between 2005 and 2016. *Gut* 2019;68:1146-51.
20. Kahrilas PJ, Pandolfino JE. Treatments for achalasia in 2017: how to choose among them. *Curr Opin Gastroenterol* 2017;33:270-6.
21. Martins RK, Ribeiro IB, DE Moura DTH, et al. Peroral (POEM) or surgical myotomy for the treatment of achalasia: a systematic review and meta-analysis. *Arq Gastroenterol* 2020;57:79-86.
22. Aiolfi A, Bona D, Riva CG, et al. Systematic Review and Bayesian network meta-analysis comparing laparoscopic Heller myotomy, pneumatic dilatation, and peroral endoscopic myotomy for esophageal achalasia. *J Laparoendosc Adv Surg Tech A* 2020;30:147-55.
23. Zhong C, Tan S, Huang S, et al. Peroral endoscopic myotomy versus pneumatic dilatation for achalasia: a systematic review and meta-analysis. *Eur J Gastroenterol Hepatol* 2020;32:1413-21.
24. Nurczyk K, Patti MG. Surgical management of achalasia. *Ann Gastroenterol Surg* 2020;4:343-51.
25. Gillies CL, Farrukh A, Abrams KR, et al. Risk of oesophageal cancer in achalasia cardia: A meta-analysis. *JGH Open* 2019;3:196-200.
26. Yeung JC, Finley C, Hanna WC, et al. Treatment choices and outcomes of patients with manometrically diagnosed achalasia. *Dis Esophagus* 2016;29:472-8.
27. El Zein M, Kumbhari V, Ngamruengphong S, et al. Learning curve for peroral endoscopic myotomy. *Endosc Int Open* 2016;4:E577-82.
28. Lv H, Zhao N, Zheng Z, et al. Analysis of the learning curve for peroral endoscopic myotomy for esophageal achalasia: Single-center, two operator experience. *Dig Endosc* 2017;29:299-306.
29. Liu Z, Zhang X, Zhang W, et al. Comprehensive evaluation of the learning curve for peroral endoscopic myotomy. *Clin Gastroenterol Hepatol* 2018;16:1420-6.e2.
30. Patel KS, Calixte R, Modayil RJ, et al. The light at the end of the tunnel: a single-operator learning curve analysis for per oral endoscopic myotomy. *Gastrointest Endosc* 2015;81:1181-7.
31. *Montgomery v Lanarkshire Health Board* (2015). Available

- online: https://en.wikipedia.org/wiki/Montgomery_v_Lanarkshire_Health_Board
32. Ahmed F, Abel GA, Lloyd CE, et al. Does the availability of a South Asian language in practices improve doctor-patient communication from South Asian patients? Cross sectional analysis of a national patient survey in English general practices? *BMC Fam Pract* 2015;16:55.
 33. Bansal N, Bhopal R, Netto G, et al. Disparate patterns of hospitalisation reflect unmet needs and persistent inequalities in mental health care; the Scottish health and ethnicity study. *Ethn Health* 2014;19:217-39.
 34. Furegato M, Chen Y, Mohammed H, et al. Examining the role of socioeconomic deprivation in ethnic differences in sexually transmitted infection diagnosis rates in England; evidence from surveillance data. *Epidemiol Infect* 2016;144:3253-62.
 35. Harris AR, Bowley DM, Stannard A, et al. Socioeconomic deprivation adversely affects survival of patients with rectal cancer. *Brit J Surg* 2009;96:763-8.
 36. Krieger N. Discrimination and health inequalities. In: *Social Epidemiology* Berkman LF, Kawachi I, Glymour MM (eds). 2nd edition. Oxford: Oxford University Press, 2014:63-125.
 37. Fowler AJ, Agha RA, Camm CF, et al. The UK Freedom of Information Act (2000) in healthcare research: a systematic review. *BMJ Open* 2013;3:e002967.
 38. Meijer A. Transparency. In: *Oxford Handbook of Public Accountability*. Bovens M, Goodin RE, Scillemans T (ed). Oxford, UK: Oxford University Press, 2014:507-24.
 39. Pasquier M, Villeneuve JP. Organisational barriers to transparency a typology and analysis of organizational behaviour tending to prevent or restrict access to information. *Internat Rev Admin Sci* 2007;78:147-62.
 40. Jain M, Baijal N, Srinivas M, et al. Retrospective study on symptoms and treatment modalities used and short-term follow up of achalasia cardia in Indian setting. *JGH Open* 2020;4:856-9.
 41. Udayaraj U, Pruthi R, Casula A, et al. UK Renal Registry 16th annual report: chapter 6 demographics and outcomes of patients from different ethnic groups on renal replacement therapy in the UK. *Nephron Clin Pract* 2013;125:111-25.
 42. Das-Munshi J, Bhugra D, et al. Ethnic minority inequalities in access to treatments for schizophrenia and schizoaffective disorders: findings from a nationally representative cross-sectional study. *BMC Med* 2018;16:55.
 43. Panaccione R, Gregor JC, Reynolds RP, et al. Intrasphincteric botulinum toxin versus pneumatic dilatation for achalasia: a cost minimization analysis. *Gastrointest Endosc* 1999;50:492-8.
 44. O'Connor JB, Singer ME, Imperiale TF, et al. The cost-effectiveness of treatment strategies for achalasia. *Dig Dis Sci* 2002;47:1516-25.
 45. van Ryn M. Research in the provider contribution to race/ethnicity disparities in medical care. *Med Care* 2002;40:1140-51.
 46. Worth A, Irshad T, Bhopal R, et al. Vulnerability and access to care for South Asian Sikh and Muslim patients with life limiting illness in Scotland: prospective longitudinal qualitative study. *BMJ* 2009;338:b183.
 47. Madhok R, Hameed A, Bhopal R. Satisfaction with health services among the Pakistani population in Middlesbrough England. *J Public Health Med* 1998;20:295-301.
 48. Burholt V, Wenger GC, Shah Z. Families and Migration: Older People from South Asia. Department for International Development (DFID). Project ESA 15 United Kingdom. Regional Report No. 2 Older Punjabi immigrants in Birmingham 2002. Available online: <https://assets.publishing.service.gov.uk/media/57a08d3ced915d3cfd0018dc/R7655GujaratiUKreport.pdf>
 49. Hawthorne K. Effect of culturally appropriate health education on glycaemic control and knowledge of diabetes in British Pakistani women with type 2 diabetes mellitus. *Health Educ Res* 2001;16:373-81.
 50. Farrukh A, Miodrag A. Collateral histories taken from patients' relatives: processes, requirements and evidence of discrimination. *J Clin Comm Care* 2019. doi:10.32474/JCCM.2019.01.000105.
 51. Bourke G, Worthy B, Hazell R. Making Freedom of Information requests: A guide for academic researchers. The Constitution Unit, University College, London, 2012. Available online: <https://www.ucl.ac.uk/constitution-unit/sites/constitution-unit/files/academics-guide-to-foi.pdf>

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