

# BMJ Open Sociodemographic differences in symptom severity and duration among women referred to secondary care for menorrhagia in England and Wales: a cohort study from the National Heavy Menstrual Bleeding Audit

Amit Kiran,<sup>1,2</sup> Rebecca Sally Geary,<sup>1,2</sup> Ipek Gurol-Urganci,<sup>1,2</sup> David A Cromwell,<sup>1,2</sup> Loveleen Bansi-Matharu,<sup>3</sup> Judy Shakespeare,<sup>4</sup> Tahir Mahmood,<sup>2</sup> Jan van der Meulen<sup>1,2</sup>

**To cite:** Kiran A, Geary RS, Gurol-Urganci I, *et al*. Sociodemographic differences in symptom severity and duration among women referred to secondary care for menorrhagia in England and Wales: a cohort study from the National Heavy Menstrual Bleeding Audit. *BMJ Open* 2018;**8**:e018444. doi:10.1136/bmjopen-2017-018444

► Prepublication history for this paper is available online. To view these files, please visit the journal online (<http://dx.doi.org/10.1136/bmjopen-2017-018444>).

AK and RSG contributed equally.

Received 29 June 2017

Revised 11 December 2017

Accepted 19 December 2017



<sup>1</sup>Department of Health Services Research and Policy, London School of Hygiene and Tropical Medicine, London, UK

<sup>2</sup>Lindsay Stewart Centre for Audit and Clinical Informatics, Royal College of Obstetricians and Gynaecologists, London, UK

<sup>3</sup>Institute of Epidemiology and Health, University College London, London, UK

<sup>4</sup>Royal College of General Practitioners, London, UK

## Correspondence to

Dr Rebecca Sally Geary;  
[rebecca.geary@lshtm.ac.uk](mailto:rebecca.geary@lshtm.ac.uk)

## ABSTRACT

**Objective** To examine symptom severity and duration at time of referral to secondary care for heavy menstrual bleeding (HMB) by socioeconomic deprivation, age and ethnicity

**Design** Cohort analysis of data from the National HMB Audit linked to Hospital Episode Statistics data.

**Setting** English and Welsh National Health Services (secondary care): February 2011 to January 2012.

**Participants** 15 325 women aged 18–60 years in England and Wales who had a new referral for HMB to a gynaecology outpatient department

**Methods** Multivariable linear regression to calculate adjusted differences in mean symptom severity and quality of life scores at first outpatient visit. Multivariable logistic regression to calculate adjusted ORs. Adjustment for body mass index, parity and comorbidities.

**Primary outcome measures** Mean symptom severity score (0=best, 100=worst), mean condition-specific quality of life score (0=worst, 100=best) and symptom duration ( $\geq 1$  year).

**Results** Women were on average 42 years old and 12% reported minority ethnic backgrounds. Mean symptom severity and condition-specific quality of life scores were 61.8 and 34.7. Almost three-quarters of women (74%) reported having had symptoms for  $\geq 1$  year. Women from more deprived areas had more severe symptoms at their first outpatient visit (difference  $-6.1$ ; 95% CI  $-7.2$  to  $-4.9$ , between least and most deprived quintiles) and worse condition-specific quality of life (difference 6.3; 95% CI 5.1 to 7.5). Symptom severity declined with age while quality of life improved.

**Conclusions** Women living in more deprived areas reported more severe HMB symptoms and poorer quality of life at the start of treatment in secondary care. Providers should examine referral practices to explore if these differences reflect women's health-seeking behaviour or how providers decide whether or not to refer.

## Strengths and limitations of this study

- This study is the first to examine heavy menstrual bleeding (HMB) symptom severity and duration at time of referral to secondary care.
- The inclusion of patient-reported symptom severity and quality of life addresses a knowledge gap about how women feel about their HMB.
- As the data were collected by a national audit in England and Wales, the sample is relatively large, allowing comparisons between ethnic groups.
- Even though the sample size is large, the National HMB Audit recruited approximately 30% of eligible women. However, the characteristics of the women recruited were broadly representative of the UK population in terms of ethnicity and age.
- Linking audit data to administrative hospital data also allowed comparisons between socioeconomic groups.

## INTRODUCTION

Heavy menstrual bleeding (HMB) is a common condition that affects one in four women of reproductive age. In England and Wales, an estimated 50 000 women with HMB are referred from primary care to secondary care gynaecology services provided by the National Health Service (NHS) every year.<sup>1</sup> Menstrual disorders account for approximately 20% of referrals to specialist gynaecology services<sup>2</sup> and studies have found significant regional variations in use of surgical treatment within England.<sup>3</sup>

Women with HMB have significantly worse quality of life (QoL) than women with normal menstrual bleeding loss, in terms of their physical and mental health, as well as their

emotional, social and material QoL.<sup>4-7</sup> More than a third of women with HMB report severe pain.<sup>7</sup> HMB is also associated with morbidity, including anaemia and related fatigue.<sup>8,9</sup> Women with HMB experience reduced participation in social activities and their personal relationships and attendance at work can be adversely affected.<sup>10</sup>

In order to improve the QoL of women with HMB, it is important to understand both the aetiology of this condition and its management in primary and secondary care.<sup>11</sup> The prevalence of HMB and conditions which affect symptom severity has been reported to vary by ethnicity.<sup>12-15</sup> In addition, cultural norms and patient choice for treatment may vary between different groups.<sup>16,17</sup>

In this study, we used data from the National HMB Audit to examine symptom severity, QoL and symptom duration at women's first gynaecology outpatient visit for HMB. The National HMB Audit was a 4-year project (2010-2014) that assessed patient-reported outcomes and experiences of care for women with HMB in England and Wales. Our objective is to examine symptom severity and duration at the time of referral to secondary care by age, ethnicity and socioeconomic deprivation to get a better understanding of the burden of disease at the start of treatment in secondary care.

## METHODS

### Data collection

Full details of the methods used in the National HMB Audit have been reported elsewhere.<sup>1,4,18,19</sup> Women aged between 18 and 60 years in England and Wales who had a new referral for HMB to a gynaecology outpatient department were eligible to participate in the National HMB Audit. Women who had visited a gynaecology outpatient clinic for HMB within the previous 12 months were excluded. Recruitment took place between 1 February 2011 and 31 January 2012.<sup>1,19</sup>

Women who consented to participate completed a baseline questionnaire (58 questions) on age, ethnicity, duration of HMB symptoms, obstetric history, prior treatment received for HMB and comorbidities. The questionnaire also collected patient-reported HMB-specific and generic QoL measures.

Scores for symptom severity and condition-specific health-related quality of life (HRQoL) were adapted from the Uterine Fibroid Symptom and Quality of Life (UFS-QoL) questionnaire.<sup>20</sup> Of five candidate questionnaires evaluated, only the UFS-QoL could be used throughout the care pathway, measured HRQoL and was psychometrically strong.<sup>18</sup> The UFS-QoL was therefore adapted for HMB and a UK population. We conducted semi-structured interviews with women (n=7) and clinicians (n=5) and a mini focus group (n=3) with local HMB Audit coordinators to determine suitable alternative words to describe HMB, and to identify words not clearly understood in UK English. Based on this, we changed the wording to refer to 'heavy menstrual bleeding' (ie, heavy

periods) rather than 'fibroids', changed 'checking' to 'ticking'; 'soiling' to 'staining'; 'blue' to 'low'; and 'wiped out' to 'exhausted'. The adapted version performed acceptably in a psychometric evaluation. Overall, the symptom severity subscale and the HRQoL subscale of the UFS-QoL used as outcomes demonstrated the strongest psychometric properties and have been used to report the audit data. The UFS-QoL consists of eight symptom items and 29 HRQoL items. The symptom items are scored to produce a severity subscale and the HRQoL items are scored into subscales (concern, activities, energy/mood, control, self-consciousness and sexual function). The HRQoL subscales can be used separately or combined into an overall HRQoL score. We use the overall HRQoL score in this paper.

A generic HRQoL measure was derived from the European Quality of Life-5 Dimensions (EuroQoL-5 or EQ-5D).<sup>21</sup> This generic measure was used because it is the instrument recommended by the Department of Health and allows comparisons with other national studies, such as the Patient Reported Outcome Measures study of common elective surgical procedures.<sup>21</sup> Women completed the questionnaire in hospital before their consultation. Using multiple sources of data, the recruitment rate of the audit was estimated to be 31.9%.<sup>1</sup> Descriptive results from the National HMB Audit have been published elsewhere.<sup>1,4,18,19</sup>

Data from the prospective audit were linked at patient level to records from Hospital Episode Statistics (HES) and Patient Episode Database for Wales (PEDW), administrative databases that capture all inpatient and outpatient episodes in English and Welsh NHS hospitals. Data linkage was performed using deterministic linkage criteria that included NHS number, sex and date of birth.

### Measures

Symptom severity, condition-specific QoL and generic QoL scores and the reported duration of symptoms at the first outpatient visit were used as outcomes in this study. The severity and QoL scores were analysed as continuous variables. Symptom severity scores ranged from 0 (best possible score) to 100 (greatest symptom severity, worst possible score). Condition-specific QoL ranged from 0 (poorest QoL) to 100 (best QoL). Generic QoL is expressed on a scale with 0 representing death and 1 perfect health.<sup>22</sup> Women were asked, 'How long have you had symptoms of heavy menstrual bleeding', with '2 months or less', 'more than 2 months but less than 1 year', 'more than 1 year' and 'don't know' as possible response categories. For analysis, duration of symptoms was grouped as '<1 year', '≥1 year' with 'don't know' coded as missing. Levels of missing data on HMB symptoms and HRQoL were low (2.2% for severity, 4.8% for condition-specific QoL and 9.9% for generic QoL, and 3.0% for symptom duration).

Age was categorised as 18-34, 35-39, 40-44, 45-49 and ≥50 years for analysis. Women reported their ethnicity as 'white', 'mixed', 'Asian or Asian British', 'black or black

British', 'Chinese' or 'other'. For analysis, the 'mixed', 'Chinese' and 'other' groups were combined as 'other' due to small numbers of women reporting these ethnicities. Self-reported height and weight data were used to derive body mass index (BMI), categorised according to WHO groups as  $\leq 25$ , 25–30 and  $\geq 30$ .<sup>23</sup> Women reported how many times they had seen their general practitioner (GP) for HMB in the year prior to their first outpatient visit, and this was grouped as 0, 1–2, 3–4, >4 for analysis ('don't know' was coded as missing).

Women reported their parity, grouped for analysis as 'nulliparous' or 'parous'. Women were also asked, 'Have you been told by a doctor that you have any of the following: heart disease (for example angina, heart attack or heart failure), high blood pressure, lung disease (for example chronic bronchitis or emphysema), diabetes, depression, thyroid disorder, kidney disease, cancer (within the last 5 years).' For analysis, the number of comorbidities reported was grouped as 0, 1,  $\geq 2$ .

Information on socioeconomic deprivation (Index of Multiple Deprivation (IMD)) was extracted from HES and PEDW. IMD is a relative measure of deprivation for small areas across a number of domains, including income, employment, education and housing. We used quintiles of IMD (level 1=most deprived areas, level 5=least deprived areas). The methods used to calculate IMD scores in each country in the UK are similar but not directly comparable.<sup>24</sup> For analysis, we generated a combined measure of deprivation for England and Wales by assigning those in each country-specific quintile to the same quintile in a combined measure. This preserved women's relative deprivation position within each country.

### Statistical analysis

Means and SDs and proportions were used to describe the cohort. Regression analyses were used to examine the relationship between age, ethnicity and socioeconomic deprivation and each of the outcomes. For the scores representing symptom severity, condition-specific QoL and generic QoL, multivariable linear regression was used to calculate adjusted differences in mean scores. For duration of symptoms (<1 year and  $\geq 1$  year), multivariable logistic regression was used to calculate adjusted ORs. Regression models included BMI, parity and number of comorbidities as potential confounders. Levels of missing data were low (<3%) for the majority of variables with the exception of ethnicity (7% missing) and BMI (approximately 23% missing, table 1). Missing values for explanatory variables were imputed using multiple imputation by chained equations<sup>25</sup> and statistical coefficients were obtained using 10 imputed data sets and combined using Rubin's rules.<sup>26</sup>

### ETHICAL APPROVAL

The data are from the National Heavy Menstrual Bleeding (HMB) Audit. Based on the Health Research Authority's

**Table 1** Patient characteristics at the first gynaecology outpatient visit for HMB (% and number unless otherwise stated)

|   | Full cohort<br>(n=15325) |
|---|--------------------------|
| Age, mean (SD) in years                         | 42.3 (7.6)               |
| Age groups                                      |                          |
| 18–34   | 14.9 (2283)              |
| 35–39   | 12.9 (1971)              |
| 40–44   | 26.6 (4071)              |
| 45–49   | 31.3 (4794)              |
| $\geq 50$                                       | 14.4 (2206)              |
| Body mass index, mean (SD) in kg/m <sup>2</sup> | 27.3 (5.4)               |
| Body mass index, categories                     |                          |
| $\leq 25$                                       | 39.6 (4681)              |
| 25–30   | 31.7 (3739)              |
| $\geq 30$                                       | 28.7 (3392)              |
| Missing   | 3513                     |
| Parity  |                          |
| Nulliparous                                     | 17.0 (2530)              |
| Parous  | 83.0 (12 338)            |
| Missing   | 457                      |
| Number of reported comorbidities                |                          |
| 0   | 66.3 (10 165)            |
| 1   | 25.3 (3878)              |
| $\geq 2$  | 8.4 (1282)               |
| Ethnicity                                       |                          |
| White   | 88.3 (12 614)            |
| Asian or Asian British                          | 4.3 (607)                |
| Black or black British                          | 5.4 (770)                |
| Other   | 2.0 (292)                |
| Missing   | 1042                     |
| Socioeconomic deprivation (IMD)                 |                          |
| Quintile 1 (most deprived)                      | 23.5 (3418)              |
| Quintile 2                                      | 21.7 (3159)              |
| Quintile 3                                      | 20.2 (2944)              |
| Quintile 4                                      | 18.7 (2720)              |
| Quintile 5 (least deprived)                     | 15.8 (2304)              |
| Missing   | 780                      |

HMB, heavy menstrual bleeding; IMD, Index of Multiple Deprivation.

guidance, audits are regulated as standard clinical practice outside of the Research Ethics Service.<sup>27</sup>

## RESULTS

### Patient characteristics

Fifteen thousand three hundred and twenty-five eligible women completed the questionnaire at their first visit to

a gynaecology outpatient department and 15 294 (99.8%) could be linked to HES or PEDW which provided information on socioeconomic deprivation. The women's mean age was 42.3 years (SD 7.6) and BMI was 27.3 (SD 5.4) (table 1). About one in five were nulliparous and one in three reported at least one comorbidity. 11.7% of women reported a minority ethnic background, with black or black British (5.4%) and Asian or Asian British (4.3%) being the largest minority ethnic groups. Women in the two least socioeconomically deprived national quintile groups (18.7% in quintile 4 and 15.8% in quintile 5) were under-represented given that, per definition, 20% of women are expected to be in each group. The distribution of symptom severity, condition-specific QoL and generic QoL, and symptom duration by level of deprivation did not vary significantly between women in England and Wales (data not shown).

The mean score for symptom severity was 61.8 (SE 0.17) with 74.0% of women reporting that they had HMB symptoms for more than 1 year. The mean score for condition-specific QoL was 34.7 (SE: 0.18) and for generic QoL was 0.65 (SE: 0.28) (table 2).

#### Severity of symptoms and QoL by socioeconomic deprivation

Symptom severity scores gradually increased with increasing socioeconomic deprivation (table 2). Condition-specific and generic QoL scores also showed a worsening gradient according to deprivation. In other words, women living in more deprived areas reported more severe symptoms (difference -6.1; 95% CI -7.2 to -4.9, between least and most deprived quintiles) and a poorer QoL (difference 6.3; 95% CI 5.1 to 7.5) at their first gynaecology outpatient visit for HMB than those living in less deprived areas.

#### Severity of symptoms and QoL by age and ethnicity

Symptom severity showed a gradual decrease with increasing age, indicating that older women reported less severe symptoms at their first outpatient visit for HMB (difference -5.9; 95% CI -7.2 to -4.6 between oldest and youngest age groups, table 2). QoL scores based on both the condition-specific and the generic measures increased with increasing age, which shows that older women reported better QoL at their first HMB outpatient visit (difference 7.3; 95% CI 5.9 to 8.7 between oldest and youngest age groups). Symptom severity also varied by ethnicity: black and Asian women reported less severe symptoms than white women (difference compared with white women -1.9 and -2.4, respectively, table 2). Condition-specific QoL did not vary significantly by ethnicity, whereas compared with white women, Asian women reported lower generic QoL scores (table 2).

#### Duration of symptoms

Women living in the most deprived areas were slightly less likely to report having had HMB symptoms for  $\geq 1$  year than those living in the less deprived areas. Women aged between 35 and 49 years were more likely to report having

experienced HMB symptoms for  $\geq 1$  year than those younger than 35. Compared with white women, black women were more likely than white women to report symptoms for  $\geq 1$  year and Asian women were less likely.

## DISCUSSION

### Main findings

Women living in more socioeconomically deprived areas reported more severe HMB symptoms and poorer QoL at their first gynaecology outpatient visit. Older women reported less severe symptoms and better QoL than younger women. Reported symptom severity also varied by ethnicity with black and Asian women reporting less severe symptoms than women from white ethnic backgrounds.

Three quarters of the women referred to secondary care reported that they had had symptoms of HMB for at least 1 year and women living in the most deprived areas were least likely to report having had HMB symptoms for  $\geq 1$  year.

### Interpretation

More severe symptoms and poorer QoL at first outpatient visit by socioeconomic deprivation, after adjustment for possible differences in age, ethnicity and BMI, reflect that women from more deprived backgrounds report more severe problems at the start of treatment in secondary care but they were least likely to report that they had symptoms for at least 1 year. The difference in the symptom severity score between women from the least and the most deprived areas of about 6 is likely to be clinically significant, given that a difference of 5 points or more has been specified as clinically important in clinical trials.<sup>28</sup> There is evidence that people from more socioeconomically deprived backgrounds may be more accepting of symptoms, chronic pain or poorer HRQoL,<sup>29</sup> which is a possible explanation for these findings. Conversely, those from more affluent socioeconomic backgrounds have been found to report greater impact of health conditions on their QoL, which may be linked to their higher expectations about health and life in general.<sup>30</sup>

Alternative explanations are that differences in symptom severity, QoL and symptom reflect inequitable access as well as differences in the nature and causes of HMB. Age is often found to be associated with symptom severity.<sup>31 32</sup> Black women are two to three times more likely to have fibroids and endometriosis.<sup>32</sup> Accepting heavy periods as normal may vary by ethnicity and other social factors, which in turn can also lead to reluctance to seek care for HMB.<sup>16</sup> Ethnographic research suggests that some women of South Asian ethnicity do not seek health-care for HMB due to the belief that heavy periods cleanse the body.<sup>17</sup> We adjust for patient-level characteristics that may capture some of these differences but were unable to adjust for other unmeasured potential confounders.

The observation that women living in the most socioeconomically deprived areas reported the most severe symptoms but were least likely to report having had symptoms



**Table 2** Severity and duration of symptoms at the first outpatient visit, by age group, ethnicity and socioeconomic deprivation

|                                 | Severity score<br>(0 best and 100 worst)<br>(n=14 990) |                                     | Condition-specific quality of life<br>(0 worst and 100 best)<br>(n=14 586) |                                     | Generic quality of life<br>(0 death and 1 perfect health)<br>(n=13 802) |                                  | Symptoms ≥1 year<br>(n=14 866) |             |                          |          |
|---------------------------------|--|-------------------------------------|--|-------------------------------------|---|----------------------------------|--------------------------------|-------------|--------------------------|----------|
|                                 | Mean score<br>(SE)                                     | Adjusted*<br>difference<br>(95% CI) | Mean score<br>(SE)   | Adjusted*<br>difference<br>(95% CI) | Mean score<br>(SE)  | Adjusted*<br>difference (95% CI) | P value                        | % (SE)      | Adjusted*<br>OR (95% CI) | P value  |
| Total                           | 61.8 (0.17)  |                                     | 34.7 (0.18)  |                                     | 0.65 (0.28)   |                                  |                                | 74.0 (0.36) |                          |          |
| Age group                       |  |                                     |  |                                     |   |                                  |                                |             |                          |          |
| 18-34                           | 63.1 (0.44)  | -                                   | 33.2 (0.48)  | -                                   | 0.61 (0.007)  | -                                |                                | 70.7 (0.98) | -                        |          |
| 35-39                           | 62.9 (0.49)  | -1.59<br>(-2.89 to 0.29)            | 33.3 (0.51)  | 1.75<br>(0.39 to 3.10)              | 0.63 (0.008)  | 0.03<br>(0.01 to 0.05)           |                                | 74.8 (1.00) | 1.25<br>(1.09 to 1.44)   |          |
| 40-44                           | 62.5 (0.33)  | -2.17<br>(-3.30 to 1.04)            | 33.7 (0.35)  | 2.59<br>(1.40 to 3.77)              | 0.64 (0.005)  | 0.04<br>(0.02 to 0.06)           | P<0.001                        | 76.8 (0.67) | 1.39<br>(1.23 to 1.58)   | P<0.001  |
| 45-49                           | 61.3 (0.31)  | -3.36<br>(-4.47 to 2.51)            | 35.4 (0.33)  | 4.23<br>(3.06 to 5.39)              | 0.67 (0.005)  | 0.07<br>(0.05 to 0.08)           |                                | 74.2 (0.64) | 1.20<br>(1.06 to 1.35)   |          |
| ≥50                             | 59.0 (0.47)  | -5.88 (-7.19 to 4.58)               | 38.2 (0.51)  | 7.31<br>(5.93 to 8.68)              | 0.70 (0.007)  | 0.10<br>(0.07 to 0.12)           |                                | 70.9 (0.98) | 1.01<br>(0.88 to 1.16)   |          |
| Ethnicity                       |  |                                     |  |                                     |   |                                  |                                |             |                          |          |
| White                           | 61.9 (0.19)  | -                                   | 34.8 (0.20)  | -                                   | 0.66 (0.003)  | -                                |                                | 74.1 (0.38) | -                        |          |
| Black or black<br>British       | 61.5 (0.82)  | -1.93<br>(-3.51 to 0.35)            | 35.0 (0.86)  | 1.45<br>(-0.16 to 3.06)             | 0.62 (0.01)   | -0.01<br>(-0.08 to 0.02)         |                                | 79.4 (1.47) | 1.34<br>(1.11 to 1.62)   |          |
| Asian or Asian<br>British       | 60.7 (1.02)  | -2.38<br>(-4.25 to 0.51)            | 34.2 (1.07)  | 1.32<br>(-0.59 to 3.22)             | 0.58 (0.02)   | -0.05<br>(-0.88 to 0.01)         | P=0.011                        | 66.1 (1.49) | 0.70<br>(0.58 to 0.85)   | P<0.001  |
| Other                           | 61.5 (1.33)  | -0.46<br>(-3.09 to 2.16)            | 33.9 (1.41)  | -1.01<br>(-3.54 to 1.51)            | 0.60 (0.02)   | -0.05<br>(-0.30 to 0.20)         |                                | 72.3 (2.67) | 0.92<br>(0.70 to 1.20)   |          |
| Socioeconomic deprivation (IMD) |  |                                     |  |                                     |   |                                  |                                |             |                          |          |
| Quintile 1 (most<br>deprived)   | 65.5 (0.37)  | -                                   | 30.5 (0.39)  | -                                   | 0.55 (0.007)  | -                                |                                | 72.0 (0.78) | -                        |          |
| Quintile 2                      | 63.5 (0.38)  | -1.53<br>(-2.57 to 0.50)            | 33.1 (0.40)  | 1.82<br>(0.75 to 2.90)              | 0.62 (0.006)  | 0.06<br>(0.05 to 0.08)           |                                | 73.6 (0.80) | 1.11<br>(0.99 to 1.24)   |          |
| Quintile 3                      | 61.6 (0.39)  | -4.22<br>(-4.30 to 2.12)            | 35.0 (0.41)  | 3.44<br>(2.34 to 4.54)              | 0.67 (0.006)  | 0.09<br>(0.08 to 0.11)           | P<0.001                        | 75.1 (0.81) | 1.20<br>(1.06 to 1.34)   | P=0.0091 |
| Quintile 4                      | 59.5 (0.41)  | -6.02<br>(-6.02 to 3.87)            | 36.8 (0.43)  | 4.78<br>(3.66 to 5.90)              | 0.71 (0.006)  | 0.13<br>(0.12 to 0.15)           |                                | 74.5 (0.85) | 1.16<br>(1.03 to 1.31)   |          |
| Quintile 5 (least<br>deprived)  | 58.2 (0.44)  | -6.07<br>(-7.23 to 4.91)            | 38.6 (0.46)  | 6.29<br>(5.10 to 7.48)              | 0.73 (0.006)  | 0.14<br>(0.13 to 0.16)           |                                | 75.1 (0.91) | 1.21<br>(1.07 to 1.37)   |          |

\*All multivariable models were adjusted for body mass index, parity and number of comorbidities. P values based on Wald test. IMD, Index of Multiple Deprivation.

for  $\geq 1$  year may reflect the wording of the question; women were asked, 'How long have you had symptoms of heavy menstrual bleeding?' and women whose symptom severity had worsened may have reported the duration of the most recent severity, rather than the overall duration.

A key question is whether the observed differences in symptom severity and condition-specific QoL at the women's first gynaecology outpatient visit are related to differences in women's health-seeking behaviour or to differences in how GPs and gynaecologists decide on whether to refer a woman with HMB. A study of self-reported healthcare-seeking behaviour in England did not find evidence that inequality in access to secondary care according to socioeconomic or ethnic backgrounds is related to patients being less likely to go to their GP or a hospital's emergency department.<sup>33</sup> Similarly, a survey of patients with chronic joint pain found that the proportions of patients who said that they were seeking help from their GP did not differ according to their socioeconomic background.<sup>34</sup> On the other hand, a national study including 130 000 patients from more than 300 primary care practices in England found that older patients and those from more deprived areas were less likely to be referred to secondary care.<sup>35</sup>

### Implications for policy and practice

In the UK, national guidelines for the management of HMB have been developed by the National Institute for Health and Care Excellence (NICE) and the Royal College of Obstetricians and Gynaecologists (RCOG).<sup>11 36 37</sup> The National HMB Audit carried out a survey of NHS hospitals in England and Wales to find out how care for women with HMB is organised and delivered at local levels. It found that key systems such as the availability of local protocols, which specified local arrangements for patient referral and management in response to the NICE guidelines, were reported only by 30% of hospitals.<sup>38</sup> Wide variation in the investigations and treatments that were offered to women with HMB in primary care were also noted. The implementation of locally agreed referral pathways, recommended by the RCOG, will help reduce this variation.<sup>39</sup>

Women with HMB in this study reported substantially worse QoL (EQ-5D mean: 0.65, SD: 0.33) than the population average for women in England (mean: 0.85, SD: 0.003), and compared with women with incontinence (mean: 0.73, SD: 0.26).<sup>40 41</sup> This reinforces the need for interventions to focus on improving women's QoL, as recommended by recent NICE guidelines.<sup>11</sup> Obesity can be associated with HMB so health promotion interventions around diet and exercise could supplement HMB-specific interventions. Criteria for what constitutes a meaningful improvement in QoL are less clear. Awareness raising activities relating to the availability of treatments for HMB could increase healthcare seeking before symptoms become severe. This may be particularly beneficial for those from more deprived backgrounds, who may be more accepting of chronic pain and worse QoL. In highlighting differences in symptom severity at their first gynaecology outpatient visit, our findings draw attention

to the lack of an agreed threshold for referral of women with HMB to secondary care in terms of symptom severity and QoL. Routine measurement of both symptom severity and QoL may be required to stimulate greater consistency in referral thresholds but validated instruments specific to HMB are currently lacking. As there is no widely used condition-specific measure of condition-specific QoL for HMB, the National HMB Audit used the UFS-QoL questionnaire, adapted for a UK population of women with HMB.<sup>18</sup>

### Strengths and limitations

This study is the first to examine the relationship between sociodemographic factors and patient-reported HMB symptom severity, QoL and symptom duration in an outpatient setting. It used data collected by a national audit carried out in England and Wales, which produced a relatively large sample. We estimated that the National HMB Audit recruited about 30% of all eligible women. There is no direct way to compare the characteristics of the women who were recruited and those who were not. However, the characteristics of the women who were recruited were broadly representative of the UK population in terms of the distributions of ethnicity and age.<sup>42 43</sup>

Survey questionnaires were only available in the English language, so non-English speakers are likely to be under-represented. On the other hand, case ascertainment varied by provider and women from providers with higher case ascertainment (ascertainment  $>45\%$ ) were more often from minority ethnic backgrounds and more deprived areas than those referred to providers with lower case ascertainment,<sup>4</sup> which suggests that the impact of not having questionnaires in other languages is likely to be small.

### CONCLUSION

About three in four women at their first visit to a gynaecological outpatient clinic for HMB in England and Wales reported that they had symptoms at least 1 year before they were referred to secondary care. Women from more deprived areas reported more severe HMB symptoms and a poorer QoL, which demonstrates a higher burden of disease at the time of referral to secondary care. Primary and secondary care providers should examine to what extent these differences reflect barriers in access to gynaecological secondary care services or women's perceptions of their menstrual problems and health-seeking behaviour.

**Acknowledgements** We firstly thank all NHS providers and patients who participated in the National HMB Audit. We also thank the Healthcare Quality Improvement Partnership, Health and Social Care Information Centre and the Royal College of Surgeons of England for providing the authors with the data required for this study. This publication is based on data collected by or on behalf of the Healthcare Quality Improvement Partnership, who have no responsibility or liability for the accuracy, currency, reliability and/or correctness of this publication.

**Contributors** The research question was derived by TM and JvdM. Data collection was supported directly by AK, IGU, DAC and LBM and through the advice of JS, TM and JvdM. Data analysis was performed by AK, IGU and RSG. All authors contributed to the writing of the manuscript.

**Funding** The National Heavy Menstrual Bleeding (HMB) Audit was funded by the Healthcare Quality Improvement Partnership as part of the National Clinical Audit

and Patient Outcomes Programme (contract number HQIP NCA 004). The audit was led by the Royal College of Obstetricians and Gynaecologists.

**Competing interests** None declared.

**Patient consent** Detail has been removed from this case description/these case descriptions to ensure anonymity. The editors and reviewers have seen the detailed information available and are satisfied that the information backs up the case the authors are making.

**Provenance and peer review** Not commissioned; externally peer reviewed.

**Data sharing statement** The data analysed were collected as part of a national clinical audit and linked to administrative hospital data (Hospital Episode Statistics). They were shared with the authors by the Healthcare Quality Improvement Partnership, Health and Social Care Information Centre and the Royal College of Surgeons of England. The data cannot be shared further without formal application to the data providers.

**Open Access** This is an Open Access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited and the use is non-commercial. See: <http://creativecommons.org/licenses/by-nc/4.0/>

© Article author(s) (or their employer(s) unless otherwise stated in the text of the article) 2018. All rights reserved. No commercial use is permitted unless otherwise expressly granted.

## REFERENCES

- Royal College of Obstetricians and Gynaecologists, London School of Hygiene & Tropical Medicine, Ipsos MORI. *National Heavy Menstrual Bleeding Audit: Third Annual Report*. London, UK: RCOG Press, 2013.
- Coulter A, Bradlow J, Agass M, et al. Outcomes of referrals to gynaecology outpatient clinics for menstrual problems: an audit of general practice records. *Br J Obstet Gynaecol* 1991;98:789–96.
- Cromwell DA, Mahmood TA, Templeton A, et al. Surgery for menorrhagia within English regions: variation in rates of endometrial ablation and hysterectomy. *BJOG* 2009;116:1373–9.
- Royal College of Obstetricians and Gynaecologists, London School of Hygiene & Tropical Medicine, Ipsos MORI. *National Heavy Menstrual Bleeding Audit: Final Report*. London, UK: RCOG Press, 2014.
- Karlsson TS, Marions LB, Edlund MG. Heavy menstrual bleeding significantly affects quality of life. *Acta Obstet Gynecol Scand* 2014;93:52–7.
- Shankar M, Chi C, Kadir RA. Review of quality of life: menorrhagia in women with or without inherited bleeding disorders. *Haemophilia* 2008;14:15–20.
- Gokyildiz S, Aslan E, Beji NK, et al. The Effects of Menorrhagia on Women's Quality of Life: A Case-Control Study. *ISRN Obstet Gynecol* 2013;2013:918179.
- Wang W, Bourgeois T, Klima J, et al. Iron deficiency and fatigue in adolescent females with heavy menstrual bleeding. *Haemophilia* 2013;19:225–30.
- Cohen BJ, Gibor Y. Anemia and menstrual blood loss. *Obstet Gynecol Surv* 1980;35:597–618.
- Bitzer J, Serrani M, Lahav A. Women's attitudes towards heavy menstrual bleeding, and their impact on quality of life. *Open Access J Contracept* 2013;4:21–8.
- National Collaborating Centre for Women's and Children's Health, National Institute for Health and Clinical Excellence (NICE). *Heavy menstrual bleeding: assessment and management*. NICE. Clinical Guideline No. 44, 2007.
- Harlow SD, Campbell B. Ethnic differences in the duration and amount of menstrual bleeding during the postmenarcheal period. *Am J Epidemiol* 1996;144:980–8.
- National Health Service (NHS) UK. Heavy periods (menorrhagia)-Causes. 2015 <http://www.nhs.uk/Conditions/Periods-heavy/Pages/Causes.aspx> (accessed 20 Feb 2015).
- Mayo Clinic. Menorrhagia. heavy menstrual bleeding. <http://www.mayoclinic.org/diseases-conditions/menorrhagia/basics/causes/con-20021959> (accessed 20 Feb 2015).
- Apgar BS, Kaufman AH, George-Nwogu U, et al. Treatment of menorrhagia. *Am Fam Physician* 2007;75:1813–9.
- O'Flynn N. Menstrual symptoms: the importance of social factors in women's experiences. *Br J Gen Pract* 2006;56:950–7.
- Chapple A. Iron deficiency anaemia in women of South Asian descent: a qualitative study. *Ethn Health* 1998;3:199–212.
- Royal College of Obstetricians and Gynaecologists, London School of Hygiene & Tropical Medicine, Ipsos MORI. *National Heavy Menstrual Bleeding Audit: First Annual Report*. London, UK: RCOG Press, 2011.
- Royal College of Obstetricians and Gynaecologists, London School of Hygiene & Tropical Medicine, Ipsos MORI. *National Heavy Menstrual Bleeding Audit: Second Annual Report*. London, UK: RCOG Press, 2012.
- Spies JB, Coyne K, Guaou G, et al. The UFS-QOL, a new disease-specific symptom and health-related quality of life questionnaire for leiomyomata. *Obstet Gynecol* 2002;99:290–300.
- EuroQol Group. EuroQol--a new facility for the measurement of health-related quality of life. *Health Policy* 1990;16:199–208.
- Kind P, Hardman G, Macran S. *UK Population Norms for EQ-5D: York Centre for Health Economics Discussion Paper*. 172, 1992.
- World Health Organisation. BMI Classification. Global Database on Body Mass Index. [http://apps.who.int/bmi/index.jsp?introPage=intro\\_3.html](http://apps.who.int/bmi/index.jsp?introPage=intro_3.html) (accessed 6 Oct 2016).
- Payne R, Abel G. UK indices of multiple deprivation - a way to make comparisons across constituent countries easier. *Health Statistics Quarterly* 2012;53.
- Royston P. Multiple imputation of missing values: update of ice. *The Stata Journal* 2005;5:527–36.
- Rubin D. *Multiple imputation for non-response in surveys*. New York: John Wiley & Sons, 1987.
- Health Research Authority. *Defining research*. London: Health Research Authority, 2016.
- Gibbons R, et al. *A structured review of patient-reported outcome measures for people undergoing elective procedures for benign gynaecological conditions of the uterus. Report to the Department of Health*. Oxford: University of Oxford, 2010.
- Delpierre C, Lauwers-Cances V, Datta GD, et al. Using self-rated health for analysing social inequalities in health: a risk for underestimating the gap between socioeconomic groups? *J Epidemiol Community Health* 2009;63:426–32.
- Ross CE, Van Willigen M. Education and the subjective quality of life. *J Health Soc Behav* 1997;38:275–97.
- Janssen CA, Scholten PC, Heintz AP. Menorrhagia--a search for epidemiological risk markers. *Maturitas* 1997;28:19–25.
- National Institute for Health and Care Excellence (NICE). *NICE support for commissioning for heavy menstrual bleeding*, 2013.
- Adamson J, Ben-Shlomo Y, Chaturvedi N, et al. Ethnicity, socio-economic position and gender--do they affect reported health-care seeking behaviour? *Soc Sci Med* 2003;57:895–904.
- Thorstensson CA, Gooberman-Hill R, Adamson J, et al. Help-seeking behaviour among people living with chronic hip or knee pain in the community. *BMC Musculoskelet Disord* 2009;10:153.
- McBride D, Hardoon S, Walters K, et al. Explaining variation in referral from primary to secondary care: cohort study. *BMJ* 2010;341:c6267.
- National Institute for Health and Care Excellence (NICE). *Heavy Menstrual Bleeding. NICE quality standard*. 47: NICE, 2013.
- Royal College of Obstetricians and Gynaecologists. *Standards for Gynaecology. Report of a Working Party*. London, UK: RCOG, 2008.
- Cox SM, Cromwell D, Mahmood T, et al. The delivery of heavy menstrual bleeding services in England and Wales after publication of national guidelines: a survey of hospitals. *BMC Health Serv Res* 2013;13:491.
- Royal College of Obstetricians and Gynaecologists. *Advice for Heavy Menstrual Bleeding (HMB) Services and Commissioners*, 2014.
- The EuroQol Group. Self-Reported Population Health. In: Szende A, Cabases J, Janssen B, eds. *An International Perspective based on EQ-5D*. Springer Netherlands, 2014.
- Harvie HS, Shea JA, Andy UU, et al. Validity of utility measures for women with urge, stress, and mixed urinary incontinence. *Am J Obstet Gynecol* 2014;210:85.e1–85.e6.
- Office for National Statistics. *Office for National Statistics, 2001 Census: Social Focus in Brief - Ethnicity 2002*, 2002.
- Office for National Statistics. *Office for National Statistics, 2011 Census: Ethnicity and National Identity in England and Wales 2011*, 2012.