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Prevalence and knowledge of heavy menstrual bleeding among African American women

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Abstract

Objective—To assess self-reported prevalence, knowledge, and health literacy regarding heavy menstrual bleeding (HMB) among African American women.

Methods—A quantitative cross-sectional survey study was conducted. An original survey was developed and distributed to a convenience sample of African American women aged 18–60 years at a community fair in a large city in the Midwestern region of the USA.

Results—Of the 274 surveys distributed, 247 were returned, 193 of which met the inclusion criteria. Overall, 163 (84.5%) participants demonstrated adequate health literacy; however, 168 (87.0%) answered fewer than 8 of 15 knowledge questions correctly. Although 75 (38.9%) women reported seeing a clinician for HMB, 89 (46.1%) believed that there was nothing that they could do to prevent it from occurring.

Conclusion—The present study found that the proportion of HMB among participants was higher than the nationwide prevalence. However, a gap existed in knowledge of HMB among the women surveyed. The study findings indicate an opportunity for community-based education to raise awareness of HMB, its associated clinical presentations, and available treatment modalities.

Keywords

African American; Fibroids; Health literacy; Heavy menstrual bleeding; Knowledge

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Conflict of interest The authors have no conflicts of interest.

1. Introduction

Heavy menstrual bleeding (HMB) is one of the most common gynecologic disorders affecting women of reproductive age. It is subjectively defined as heavy cyclical menstrual bleeding occurring over several consecutive cycles. Objectively, it is a total blood loss of at least 80 mL per menstrual cycle or a menstrual cycle lasting longer than 7 days [1]. It is estimated that 10%–35% of US women of reproductive age experience HMB, and the condition is associated with lower quality of life, loss of productivity, and increased healthcare expenses [2–6]. Heavy menstrual bleeding accounts for up to one-third of gynecologic office visits and is the leading cause of hysterectomy in the USA [1,7]. Evidence indicates that African American women experience HMB in disproportionate numbers compared with non-Hispanic white women, which may be largely attributable to the increased prevalence of uterine fibroids among African American women and the potential biological differences in their hormonal milieu [8–12].

Despite the high prevalence of HMB, many women lack a fundamental understanding of the disorder and often present to the emergency department seeking treatment rather than obtaining preventive care in outpatient health clinics [4,13]. Patterns of ambulatory care use for HMB differ across the racial spectrum, with African American women twice as likely as non-Hispanic white women to frequent the emergency department or hospital outpatient department [13]. This discrepancy in health behavior is indicative of differences in the diverse set of factors that drive health behavior, including health literacy and health knowledge.

The Institute of Medicine defines health literacy as “the degree to which individuals have the capacity to obtain, process, and understand basic health-related decisions” [14]. Low health literacy has been linked to lower health knowledge, lower rates of medication adherence, higher hospitalization rates, and poorer control of chronic diseases [15–18]. Given the low rates of health literacy in the USA, many women who experience HMB may be health illiterate and knowledge deficient with regard to their personal health [14]. Consequently, they may be unaware of the clinical presentations associated with HMB, its potential severity, and the available treatment options.

Although there is an abundance of published material regarding the substantial impact of HMB on quality of life, its association with increased healthcare costs, and available treatment options, there are—to the best of our knowledge—no published data assessing women's fundamental understanding of the condition, particularly within the contexts of health literacy and health knowledge [4,19,20]. The aim of the present study was to assess the presence and knowledge of HMB in a cohort of African American women of reproductive and postmenopausal ages. We also sought to assess the health literacy status of the study population. We hypothesized that the proportion of HMB would be higher than the national prevalence of 10%–35% and that there would be a significant gap in HMB knowledge among the participants. In addition, we hypothesized that there would be adequate health literacy in the study population.

2. Materials and methods

The present cross-sectional survey study involved a convenience sample of female attendees at a community fair hosted by a faith-based organization on August 4, 2012, in Chicago, IL, USA. Women were recruited as they approached study personnel at a designated area and were offered a brochure describing the study. Participation was restricted to English-speaking women between the ages of 18 and 60 years who self-identified as being African American. The study was reviewed and approved by the institutional review board of Northwestern University. Verbal consent was required and obtained from all study participants.

The authors developed a survey based on current literature to assess knowledge of HMB and normal menstrual cycle characteristics. The survey was reviewed by a multidisciplinary team of experts in community-based participatory research, health communications, and gynecology. A revised survey was then developed and cognitive testing was performed with individuals who met the profile of the target participants; the survey was then further revised based on their feedback. Eligible participants were given a self-administered 53-item survey. The anonymous survey focused on 5 topics: demographic data; menstrual/HMB history; HMB knowledge; HMB attitudes and efficacy; and health literacy. The survey had not been validated.

Given the format of the survey, we opted to use a validated single-question method to assess health literacy. The question “How confident are you filling out medical forms by yourself?” is a single Likert-scale question validated by Chew et al. [21] to identify individuals with inadequate health literacy. Adequate health literacy indicates that an individual is able to read at a high-school level or higher and implies that they could probably read and understand most patient education materials. Inadequate health literacy indicates a secondary-school or lower reading level and implies that an individual might struggle with most patient education materials.

Frequency analyses were performed on all knowledge, history, and demographic items. Heavy menstrual bleeding knowledge was analyzed as composite data. Composite HMB knowledge was determined to be adequate if the participant answered at least 8 of 15 knowledge questions correctly. The Pearson χ^2 test was used to determine the interactions between composite knowledge and demographics, menstrual/HMB history, attitudes and efficacy, and health literacy. $P < 0.05$ was considered to be statistically significant. All statistical analyses were conducted using SPSS version 18 (IBM, Armonk, NY, USA).

3. Results

In total, 247 of the 274 distributed surveys were returned, giving a response rate of 90.1%. Fifty-four surveys were excluded from the data analysis because they did not meet the inclusion criteria and/or were more than 50% incomplete. Thus, the final sample size was 193. The mean age of participants was 46.5 ± 0.74 years (range, 18–60 years). In total, 186 (96.4%) participants had at least a high-school diploma or a General Equivalency Diploma and 137 (71.0%) reported an annual household income of less than US \$50,000.

Overall, 163 (84.5%) participants had adequate health literacy, as measured by the single validated Likert-scale question [21]; 134 (69.4%) reported having some form of private health insurance or public aid; 103 (53.4%) women still had menses, of whom 43 (41.8%) reported their menses to be heavy or very heavy. Using a scaled question, 29/103 (28.1%) rated their quality of life during their menstrual cycle as “fair” or “poor.”

Of all participants, 75 (38.9%) indicated that they had seen a doctor in clinic for HMB; 34 (17.6%) had presented to the emergency department for HMB and 35 (18.1%) had been hospitalized for HMB; 61 (31.6%) women indicated that they had received treatment for HMB (Figure 1A and 1B); 62 (32.1%) reported missing activities such as school or work in relation to HMB; 59 (30.6%) participants had uterine fibroids and 5 (2.6%) had adenomyosis.

Overall, 131 (67.9%) surveyed participants indicated experiencing at least 1 symptom consistent with anemia during their menstrual cycle. While most women reported fatigue (n=84 [43.5%]), some also reported headache (n=24 [12.4%]), dizziness (n=9 [4.7%]), receiving a blood transfusion (n=12 [6.2%]), and fainting (n=2 [1.0%]) (Figure 1C).

In total, 129 (66.8%) participants did not know that menstrual bleeding is considered excessive or prolonged if it lasts longer than 7 days; 165 (85.5%) did not know that a normal menstrual cycle length is defined as 24–35 days; 141 (73.1%) did not know the prevalence of HMB; 30 (15.5%) believed that HMB has no known causes, while 52 (26.9%) were unsure whether there are any known causes; 122 (63.2%) could not correctly identify the major causes of HMB from a list; 147 (76.2%) were aware of the causative relationship of HMB with anemia; 35 (18.1%) did not know that HMB can result in a blood transfusion and 62 (32.1%) were unsure.

Regarding treatment, 110 (57.0%) women could not name a treatment for HMB without a list prompt; 80 (41.5%) believed that they could name a treatment for HMB without a list prompt, although only 54 (67.5%) of these women were able to do so correctly; 114 (59.1%) knew that hysterectomy is an available treatment option for HMB, although 28 (14.5%) believed that surgery is the only available treatment option for HMB and 54 (28.0%) were unsure.

Figure 2 provides a summary of attitudes and self-efficacy regarding HMB. While 83 (43.0%) participants expressed concern over the amount of blood lost during their menstrual cycle, only 46 (23.8%) considered themselves to be at risk for HMB. A total of 140 (72.5%) participants believed that HMB is a serious health issue and 147 (76.2%) agreed that it requires medical attention. However, 89 (46.1%) did not believe that there was anything they could do to prevent HMB from occurring.

Several variables were found to have significant correlations with composite HMB knowledge: seeing a doctor for HMB ($P=0.023$); receiving treatment for HMB ($P=0.005$); knowing someone outside one's own family with HMB ($P=0.026$); and considering oneself at risk for HMB ($P<0.001$). In addition, annual household income ($P=0.030$) and health literacy ($P=0.021$) were found to correlate with composite HMB knowledge. Despite the

correlation between health literacy and HMB knowledge, 168 (87.0%) participants answered fewer than 8 of 15 knowledge questions correctly.

4. Discussion

The goal of the present community-based study was to assess health literacy and self-reported prevalence and knowledge of HMB among African American women of reproductive and postmenopausal ages. As predicted, at 38.9%, the prevalence of HMB in the study population was higher than the national prevalence of 10%–35% [4]. This is not surprising in an exclusively African American population, given the increased prevalence of uterine fibroids and the fact that HMB is a common symptom of fibroids [10,12]. Despite the high prevalence of HMB in the study population, there was a significant gap in HMB knowledge among the women surveyed.

Although the Pearson χ^2 test on health literacy and composite HMB knowledge revealed a significant correlation, a discrepancy was found between the 2 variables in the study population. Most of the women surveyed had adequate levels of health literacy but, despite this, the majority answered fewer than 8 of 15 knowledge-based questions correctly. This indicates that, while there is a link between health literacy and HMB knowledge, having adequate health literacy is not a guarantor of adequate HMB knowledge. This discovery emphasizes the need for community-based HMB education, even in populations with high levels of adequate health literacy.

Although more than 40% of premenopausal women described their menses as “heavy” or “very heavy,” only one-third of participants reported receiving treatment for HMB. One reason that women may not pursue care is that gynecologic consultation is perceived as being a step toward obtaining a hysterectomy [22]. Known cultural norms surrounding menstruation may be another contributing factor to African American women not seeking care for HMB because some African American women regard their menses as a needed anatomic cleansing process [23]. Thus, it should be considered that these women may be more tolerant of HMB if they consider it necessary to rid their bodies of unclean elements. African American women also describe a “culture of silence” surrounding menstruation and indicate that communication among women regarding menstruation is poor [23]. This communication deficit highlights a lack of information exchange and further indicates an opportunity for HMB education in this population.

The present study was novel in that it addressed knowledge of a common gynecologic condition—HMB—that has not been previously explored in any population, to the best of our knowledge. We sought to understand HMB in African American women by investigating its prevalence in this population, in addition to women's attitudes, health literacy, and levels of HMB knowledge. The findings enable us to suggest interventions to improve women's HMB knowledge and increase their sense of self-efficacy as it pertains to this condition. The findings present an opportunity for HMB education, with a focus on available treatment options, in a population with high levels of adequate health literacy.

While the present study provides much-needed information on women's knowledge of HMB, it does have limitations. One limitation arises from the fact that the survey used in the study was developed by the authors and had not been validated. Additionally, the population surveyed was exclusively African American, predominantly low-income, and located in a single community. Therefore, the findings may not be generalizable to the population of American women as a whole. Self-reported prevalence would predictably be different in populations of different racial backgrounds, regardless of health literacy and knowledge status. In addition, the convenience sampling used in the present study may mean that the results are not representative of the entire population of African American women. The data were also self-reported and not objectively measured. Therefore, over- or under-reporting of HMB is a consideration.

In summary, the self-reported prevalence of HMB in the study population exceeded the national prevalence and was associated with a significant lack of HMB knowledge among study participants. There was also a low level of self-efficacy pertaining to HMB, which is concerning given the complexity of the patient–clinician shared decision-making process required in deciding on one of the diverse treatment options available. In the study population, the knowledge deficit was not simply a result of poor health literacy and presents an opportunity for a multimodal intervention regarding HMB education in order to promote better health outcomes in women with this menstrual dysfunction. We believe that education would help to support an increase in the sense of self-efficacy as it pertains to HMB in this population, resulting in more women seeking and receiving treatment for HMB, thereby alleviating their symptoms and improving their quality of life.

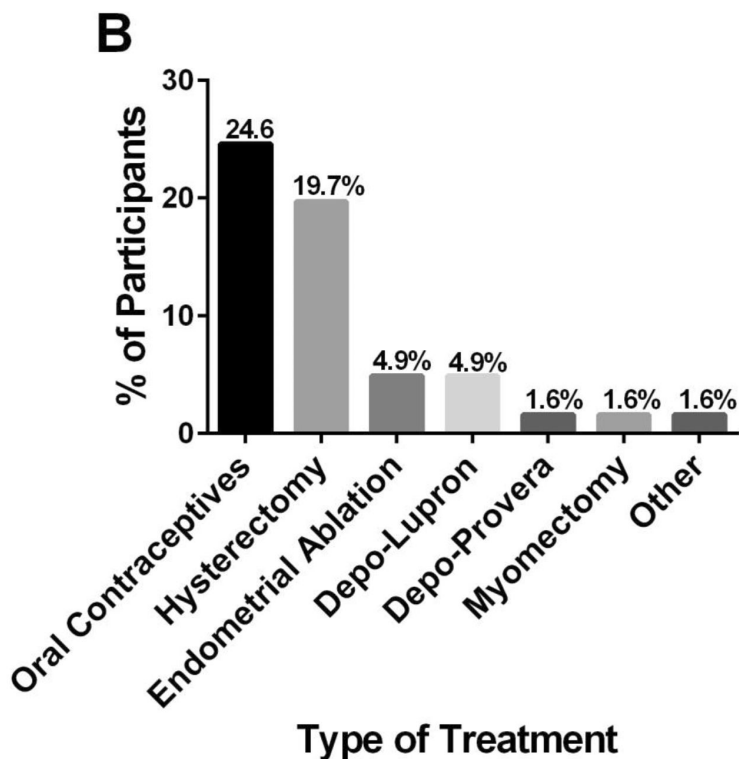
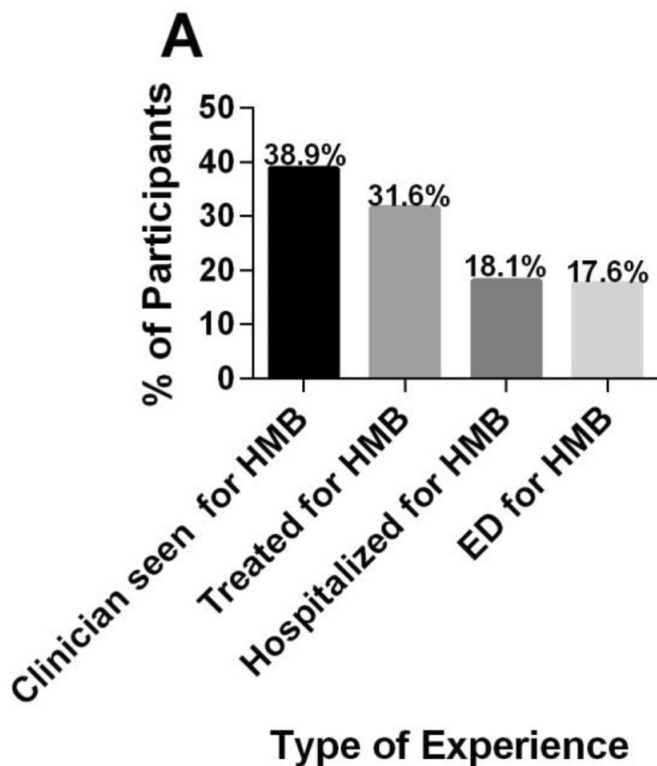
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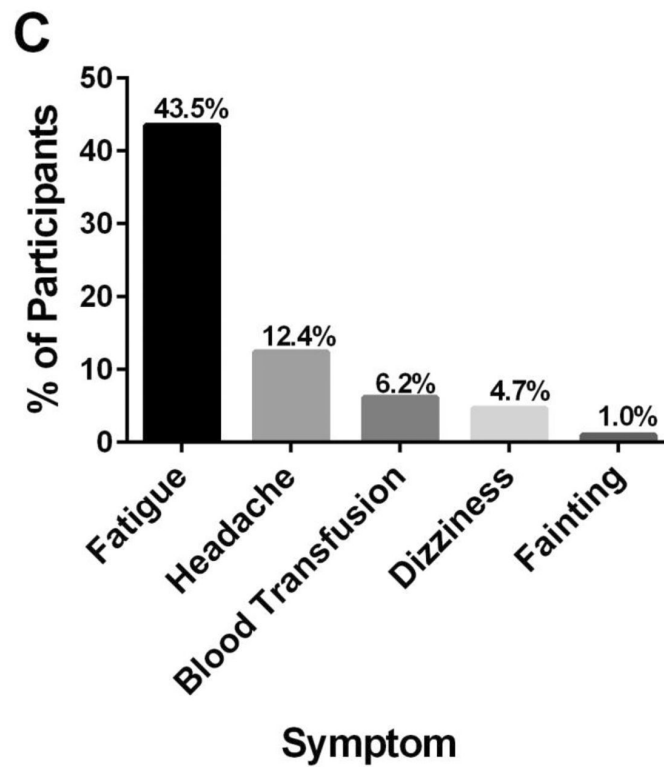


Figure 1.

Participant menstrual/heavy menstrual bleeding (HMB) history. (A) Percentage of participants who had seen a doctor in clinic, presented to the emergency department (ED), been hospitalized, and/or been treated for HMB. (B) Percentage of participants who indicated that they had received 1 or more types of treatment for HMB. (C) Percentage of participants who indicated that they had experienced 1 or more symptoms consistent with anemia during their menstrual cycle.

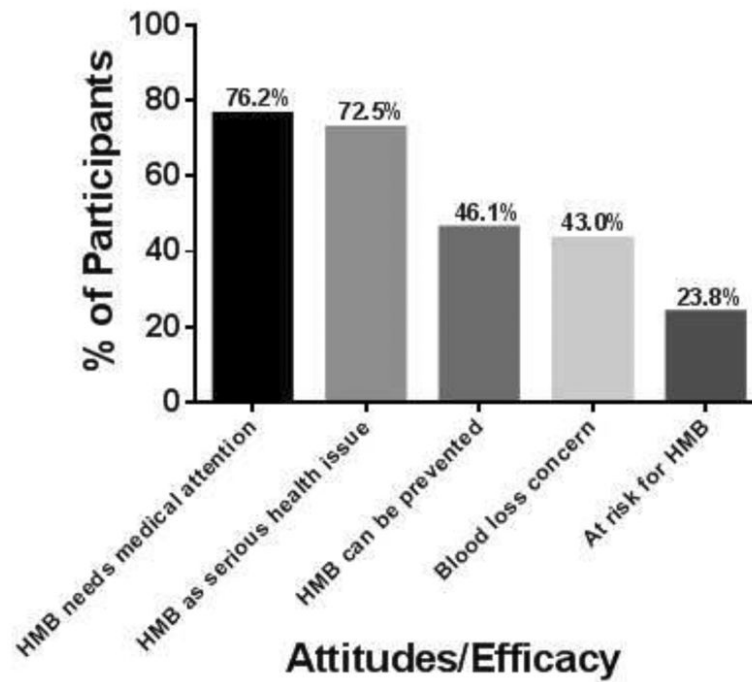


Figure 2. Heavy menstrual bleeding (HMB) attitudes and efficacy. The graph shows the beliefs of participants regarding HMB and their assessments of self-efficacy and risk.