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Developing a multidisciplinary Young Women's Blood Disorders Program: a single-centre approach with guidance for other centres

A. ZIA,*†‡ M. LAU,*‡ J. JOURNEYCAKE,*†‡ R. SARODE,§ J. MARSHALL,‡ N. DE SIMONE,§ E. WILSON,¶ A. WINBORN‡ and P. KOUIDES**

**Department of Pediatrics; †Division of Hematology/Oncology, The University of Texas Southwestern Medical Center; ‡Children's Medical Center; §Department of Pathology; ¶Department of Obstetrics and Gynecology, The University of Texas Southwestern Medical Center, Dallas, TX; and **Mary M. Gooley Hemophilia Center, University of Rochester School of Medicine, Rochester, NY, USA*

Introduction: Bleeding from the reproductive tract in women is a natural event, generally occurring with menstruation and childbirth. Women with an underlying bleeding disorder may experience heavy menstrual bleeding (HMB) and thereby, unacceptable blood loss. Up to 20% of US women with abnormal uterine bleeding and a normal gynaecological exam may have an underlying bleeding disorder corresponding to almost 2–3 million American women. These females face many obstacles in achieving optimum medical care for their problems. A haematologist may not evaluate these women as they are treated symptomatically. Recognition of an underlying bleeding disorder is not straightforward and many come to attention after serious bleeding events. Although mortality from HMB is uncommon, the true burden of HMB is its impact on health-related quality of life. To address these issues, women with HMB require a comprehensive approach to their care. **Methods:** These reasons compelled us to institute a multidisciplinary Young Women's Blood Disorders (YWBD) Program at our institution. **Results:** Herein, we describe the process of developing this program involving paediatric haematology, adolescent medicine and paediatric/adolescent gynaecology, and the expertise of a laboratory coagulationist, a nutritionist and nursing professionals. We also describe our experience with patient selection, the role of each specialty in the program, our approach to testing, the coordination of care and overall management of this patient population. Lastly, we propose metrics that could be followed in justifying the support of such a program. **Conclusions:** There is a growing need to offer comprehensive care to women with HMB and blood disorders. The YWBD program at our institution appears to be successful in delivering optimal care to young women affected with HMB.

Keywords: abnormal uterine bleeding, bleeding disorders, comprehensive care, heavy menstrual bleeding

Introduction

Heavy menstrual bleeding (HMB) represents a major public health problem [1]. The morbidity of this condition is pronounced, and includes a variety of medical complications such as chronic iron deficiency, severe anaemia with the potential risk of undergoing hysterectomy and life-threatening bleeding with surgeries. Women with HMB have impaired social, sexual and occupational lives and have a higher incidence of anxiety and depression [2,3]. In total, this translates into increased healthcare utilization and lost time from work and school [4,5]. The prevalence of bleeding disorders among older women with HMB is estimated to be up to 20% [6,7]. In 2001, the American College of Obstetricians and Gynecologists (ACOG) published a statement recommending von Willebrand disease (VWD) screening in adolescents with severe HMB [8]. In 2006, the American Academy of Pediatrics (AAP) in collaboration with ACOG published a position statement advising that haematological disorders, particularly VWD be considered in subjects with HMB, especially at menarche [9]. Recent findings suggest that in female carriers of haemophilia, not only clotting factor levels at the extreme of distribution,

Correspondence: Ayesha Zia, MD, Division of Hematology/Oncology, The University of Texas Southwestern Medical Center, 5323 Harry Hines Blvd, Dallas, TX, USA.
Tel.:+1 469 303 4400; fax: +1 469 303 4420;
e-mail: ayesha.zia@utsouthwestern.edu

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resembling mild haemophilia, but also mildly reduced clotting factor levels between 40 and 60% are associated with increased bleeding [10–12]. A Center of Disease Control (CDC) survey of United States based haemophilia treatment centre (HTC) services provided for women confirmed the anecdotal reports about delayed diagnosis of VWD [13]. Since women with bleeding disorders are recognized as having distinct healthcare needs, federally funded HTCs established to promote the health and well being of males with haemophilia, have expanded their services to include such women. The overall female HTC population grew 346% from 1990 onwards, but females still comprised only 31% of all HTC patients in 2010 [14]. Screening for inherited bleeding disorders is still underperformed, done in <25% of subjects with severe HMB [15]. Inherited bleeding disorders and HMB in women have started to receive greater attention in the past decade and a multidisciplinary approach to manage gynaecological and obstetric issues in such women is recommended [16–18].

An evaluation of care for young women with HMB at our institution indicated that depending on the referral stream, such women maybe offered and receive different diagnostic work-up and therapies. There may be a failure to recognize or even consider a diagnosis of bleeding disorder either by patients or providers until clinically significant anaemia or bleeding events develop. There may also be a reluctance to work-up the patient for a disorder of haemostasis if the bleeding pattern is anovulatory on the supposition that semi-empiric hormonal therapy is the first step in evaluation and management. Therefore, to improve clinical outcomes and develop a unified management approach regardless of referral stream, we developed a multidisciplinary 'Young Women's Blood Disorders (YWBD) Program' at our institution under the auspices of our HTC. Herein, we describe the assembly of the necessary elements for a successful coordinated and combined team approach at our institution.

Combined clinical care

Service scope

Early on, we realized that the establishment of a dedicated YWBD programme required institutional clarity regarding the scope of the programme, which needed to reflect the clinical specialties of the institution, the expertise of the available staff, and the ability of the team to serve the needs of this patient population. Key considerations included: (1) the type of patients evaluated (inpatients, outpatients or both); and (2) the referral process to the programme by non-programme healthcare providers (mandatory or optional).

Patient selection

The first issue we addressed was the target patient population to be seen in the multidisciplinary YWBD programme. We did not want to limit our evaluation to those with an already established bleeding disorder, as we wanted to capture all undiagnosed cases. Recognizing that all guidelines acknowledge HMB as the most common symptom that women with an underlying bleeding disorder experience, we wanted to clearly define HMB. There has been a long-standing confusion concerning terminologies and definitions surrounding 'menorrhagia', a loosely defined term used for HMB. 'Dysfunctional uterine bleeding' is associated with adolescents and often implies anovulatory bleeding. For our purposes, we decided to adopt the International Federation of Gynecology and Obstetrics (FIGO) terminologies and classification system for our programme. These have been published after several years of robust international cooperation and consensus forming in 2011 [19]. Abnormal uterine bleeding or HMB are the preferred overarching terms and the work-up of HMB or AUB proceeds within the realm of PALM-COEIN classification; PALM indicates structural causes: polyp, adenomyosis, leiomyoma and malignancy, and COEIN indicates non-structural causes: coagulopathy, ovulatory dysfunction, endometrial, iatrogenic, and not yet classified. We defined HMB based on existing guidelines as periods lasting more than 7 days, soaking through a pad or tampon under 2 h or soaking through bed clothes, passing clots and ferritin below normal limits or anaemia [20]. Women, especially younger adolescents, usually do not have an objective "yardstick" against which to measure their menstrual experience, therefore a patient's perception of increased menstrual loss [19] was also categorized as HMB, and considered a criterion for evaluation.

We then decided that adolescent girls achieving menarche until age 21 years, with any of the above features consistent with HMB would be eligible for the YWBD programme. Additional eligibility criteria included: family history of an established bleeding disorder, haemorrhagic ovarian cysts, haemorrhage requiring emergency department (ED) visit or hospitalization and failure to respond to conventional management of HMB [21,22]. In addition, as women may develop venous thromboembolism as a result of hormonal therapy initiated for abnormal uterine bleeding (AUB) or experience AUB as a result of anticoagulation, we decided to include this important patient population to be managed in this clinic as well (Table 1).

Coordination between haematology and adolescent medicine and gynaecology

Next, given that HMB is the common denominator among these patients, we clearly articulated and

Table 1. Eligibility criteria for evaluation in the Young Women's Blood Disorders Clinical Program.

- Any HMB-self perceived or as perceived by the referring provider
- Any acute HMB that leads to an emergency department visit or hospitalization
- Persistent and recurrent breakthrough menstrual bleeding on hormonal therapy
- Any HMB with a positive family history of HMB
- Any HMB in a patient with an established bleeding disorder or a family history of bleeding disorder
- Any HMB in the presence of known thrombophilia
- Any HMB in the presence of history of VTE or anticoagulant therapy

HMB, heavy menstrual bleeding.

documented the relationship between haematology and adolescent medicine and/or gynaecology in seeing these patients within the clinic. We secured agreement regarding which service will decide management of acute HMB presenting to the ED as well as the type, timing and escalation of hormonal therapy and diagnostic work-up. We also decided that provision of a scheduled outpatient clinic supports optimal management by facilitating appropriate work-up and education for patients, assesses the suitability of monitoring plans and helps develop effective relationships between patients and the managing team. Lastly, we decided on utilizing standardized diagnostic and therapeutic management informed by evidence-based clinical practice guidelines (CPGs) for consistency of our approach. Institutional guidelines were also incorporated to address local requirements.

Implementation of evidence-based guidelines for management

Testing approach. Our testing approach incorporates a history, physical exam and laboratory tests, and revolves around the pathophysiological underpinnings of HMB and proceeds within the realm of PALM-COEIN classification (Fig. 1). As history alone may not be the best tool for assessing menstrual bleeding, especially in the adolescent population [20], we implemented the use of two HMB-specific tools. The pictorial blood assessment chart (PBAC) is a semi-quantitative method, which allows women to track the number of pads or tampons used for a menstrual period, as well as the degree of soiling [23]. Although there are advantages and disadvantages to using the PBAC, an alternative is the much more complicated alkaline haematin test, which is not practical for clinical use. PBAC has proven to be superior to patient's verbal history [24],has also been validated for use in clinical practise [25], specifically, in the adolescent population to quantify menstrual blood loss objectively [26]. As HMB can be seen in women with or without a bleeding disorder, to capture a 'significant bleeding history', we elected to use the Philip screening tool (patient-administered) [27] and a provider administered bleeding assessment tool (BAT), developed by International Society of Thrombosis and Haemostasis (ISTH), which may be useful for diagnostic purposes in children [28,29]. The ISTH BAT instrument can be found at http://c.ymcdn.com/sites/www.isth.org/resource/resmgr/ssc/isth-ssc_bleeding_assessment.pdf (accessed June 20th, 2015). This instrument, prospectively evaluated in children, was able to discriminate between no bleeding disorder and a possible bleeding disorder with acceptable accuracy and showed that a bleeding score <2 in children makes a bleeding disorder unlikely [30]. As fatigue and quality of life (QoL) impairment is greater in these patients, when compared to healthy adults and young women without HMB [31], we decided to include validated patient-reported outcome tools in routine clinical care [32,33]. These tools are mailed out to patients before the clinic appointment to avoid rushing the patient during a busy clinic. These assessments are carried out at each visit until the diagnosis of an underlying bleeding disorder is established, iron deficiency and/or anaemia corrected and HMB is controlled.

We decided to perform VWD testing and platelet aggregation studies in every patient, based on previously reported data showing these to be highly prevalent in women with HMB [34–36]. It was decided that we would not perform VWD testing in close proximity to the acute bleeding episode, especially one that requires ED visit or hospitalization. VWF is an acute phase reactant and transient increases are common under stress. The effect of oral contraceptives (OCPs) on VWF is dose dependent and VWF levels have been shown to increase with OCPs that contain ≥50 μg of oestrogen [37]. For this reason, we also do not test for VWD during or soon after high-dose oestrogen pulse or during an OCP wean. Testing is otherwise performed irrespective of the phase of menstrual cycle [38] and while on once a day OCPs. We decided to repeat appropriately timed VWD testing at least twice given assay limitations, and platelet aggregation testing only once unless abnormal. Lastly, the FIGO (PALM-COIEN) aetiological classification is employed to work-up for structural and non-structural causes of HMB in parallel, based on patient's age.

Collaborative care team

Key to the success of our multidisciplinary, combined clinic is not only the effective collaboration between adolescent medicine, gynaecology and haematology staffs as noted above, but also the collaboration between several other specialists, including coagulation medicine, a nutritionist, nursing manager and a nursing coordinator (Fig. 2). The paediatric haematologist and either the adolescent medicine specialist or gynaecologist evaluates each patient during dedicated clinic days each month. We strive to schedule younger adolescents (postmenarcheal girls between ages

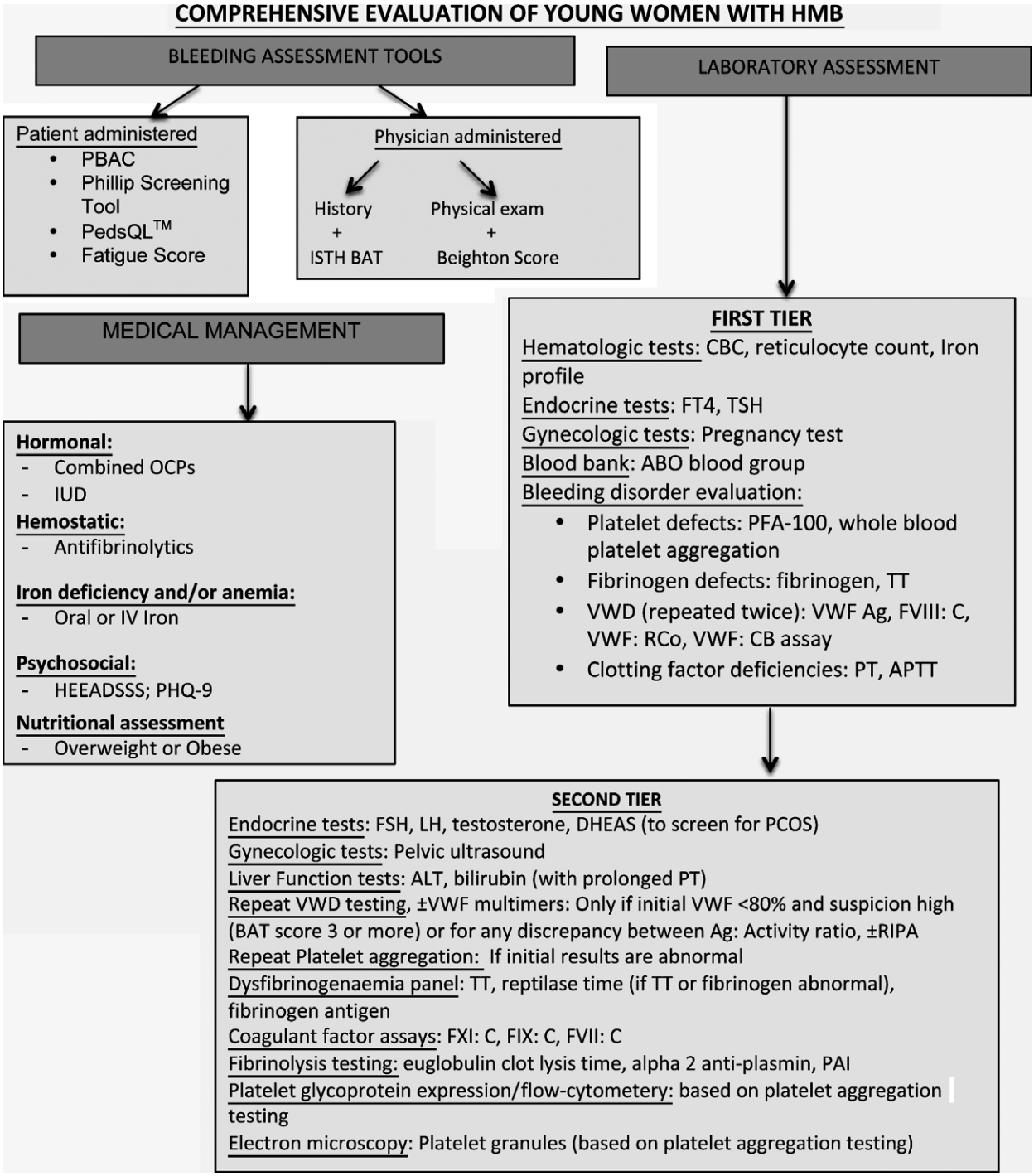

Fig. 1. Testing and management algorithm for young women with heavy menstrual bleeding.

9–15 years) in our clinic with the adolescent medicine specialist, whereas older adolescents, between ages 16 through 21 years, are scheduled with the gynaecologist. This arbitrary cut-off is optional and depending on the needs, each patient may see one specialist or the other or sometimes, both. How these specialties collaborate to address the needs of our patients' in the YWBD Clinic is described below.

Multidisciplinary team

Haematology. A paediatric haematologist with specific expertise in haemostasis thrombosis is instrumental in the proper assessment and management of underlying bleeding disorders. We carefully selected patient eligibility criteria for evaluation in the programme, developed a bleeding disorder testing algorithm,

Fig. 2. Ideal team members for a Young Women's Blood Disorders Clinical Program.

frequency and timing of testing and established protocols for standardized management.

Adolescent medicine and gynaecology. Consensus guidelines recommend that the management of HMB in females with an underlying bleeding disorder, requires the combined expertise of a haematologist and a gynaecologist [39–42]. We, however, decided that the expertise of both adolescent medicine and gynaecology was equally important in the care of women with HMB. Adolescent medicine specialists are trained to identify and treat depression in adolescents, therefore we rely on their expertise to assess patients for these associated conditions. The adolescent medicine specialist also performs a psychosocial assessment at each visit using the HEEADSSS (Home environment, Education, Eating, peer-related Activities, Drugs, Sexuality, Suicide/depression and Safety from injury and violence) format, to identify any other high-risk behaviour, which may be addressed at the same time, given that these may be underlying causes of HMB. Lastly, our adolescent medicine specialist provided input on the essential equipment for the proper physical assessment of females with HMB in a haematology clinic setting. Heavy menstrual bleeding often requires escalation of therapy; for example, the levonorgesterel intrauterine device (IUD) has been shown to be effective in treating HMB and is now considered for all age groups [43]. This and other surgical interventions, including emergent control of uterine bleeding, can be undertaken by gynaecology both on an outpatient and inpatient basis.

Both specialists critically reviewed the eligibility criteria for patients that need to be evaluated in the multidisciplinary format. Other key role of these specialists is the individualization of the contraceptive management of HMB for each inpatient and outpatient, based on previously published data and their own clinical experience. They are also on-call, available to tailor therapy and provide recommendations for outpatient calls related to break though bleeding, including interpretation of pelvic exam imaging.

Coagulation medicine specialist. Coagulation testing is complex and requires careful considerations before a diagnosis of an underlying bleeding disorder is established or ruled out. It also requires on site sample processing, analysis and ready availability, therefore it was important to have a coagulationist on site as part of the team and have a platform where the results of complex tests can be discussed. Our coagulation expert helped develop and review the testing algorithm (Fig. 1) for the work-up of these patients. Difficult cases are then discussed in a weekly pathology conference including conflicting results and optimal timing and frequency of follow-up tests.

Nursing manager and coordinator. Our *nursing manager* played a critical role in the organization of the haematology clinic to be able to accommodate this unique patient population with respect to office space, timing of visits, and overall flow of the clinic. The

nursing manager trained the multidisciplinary healthcare team members, including new patient coordinators for haematology and adolescent medicine and gynaecology on the eligibility criteria for incoming referrals. A hospital wide awareness campaign was initiated in which all departments were introduced to this new clinical programme and informed of its start date. Visits to community-based paediatricians were also deemed important to the success of our institution's YWBD clinic and were planned accordingly.

We also decided to have a dedicated *nurse coordinator* for this programme, who would receive all patient calls, provide education to patients and their families and coordinate care. The shared expertise of nursing, medical and allied health professionals facilitates the patients' and families' overall learning about these disorders and ultimately contributes to improved efficacy of treatment. The HTC nurse takes over once the diagnosis of an underlying bleeding disorder is confirmed or the adolescent medicine or gynaecology nurse if such a diagnosis is excluded. The follow-up care of young women ultimately diagnosed with an underlying bleeding disorder continues with the YWBD programme.

Nutritionist. The importance of a nutritionist was realized soon after the launch of the outpatient clinic and has since, become an important member of the multidisciplinary team. While the association between obesity and HMB is not well documented, obesity and anovulatory cycles often go hand-in-hand. Moreover, a poor diet often compounds iron deficiency from HMB. The programme nutritionist helped review dietary hand-outs including those that outline iron-rich foods and appropriate iron replacement regimens when indicated and works with overweight and obese young women being evaluated in the clinic with dietary choices and initiates referral to the childhood obesity clinic as deemed appropriate.

Local protocol development and implementation

Data on therapeutic management of women and particularly in adolescents with underlying bleeding disorders are scarce. We therefore derived HMB treatment protocols from existing consensus management guidelines developed by professional and scientific organizations. Our aim was to standardize therapy locally and then, uniformly recommend these protocols to the emergency department physicians, general paediatricians and the hospitalists within our institution.

Acute HMB with haemodynamic compromise

Studies of treatments for acute HMB are limited, and only one treatment, intravenous conjugated equine oestrogen is specifically approved by the U.S. Food and Drug Administration for the treatment of acute AUB [44]. Other options include combined oral contraceptives and oral progestins [45]. Therefore, we decided upon various regimens depicted in Table 2.

Acute HMB on an outpatient basis

Management of medically stable patients or those in an outpatient setting occurs along the same lines with hormonal therapy as the mainstay of management (Table 3). We choose to offer antifibrinolytics if hormonal therapy is not effective in controlling bleeding or if families desire non-hormonal options for control of HMB when a bleeding disorder is not yet established. For those with a history of VTE or thrombophilia, we start progestins, hormonal implants or intrauterine devices based on the patient's age, lifestyle and wishes of the patient and family. These are addressed and discussed by either the adolescent specialist or gynaecologist.

Table 2. Management of acute heavy menstrual bleeding.

First line
Hormonal therapy (Any of the following regimens in consultation with adolescent medicine/gynaecology)
IV conjugated oestrogen (Premarin): 25 mg every 4–6 h until bleeding stops, re-evaluate continuation at 48 h
Any 30 μg ethinyl oestradiol containing combination OCP: one tablet PO Q6H until bleeding stops, re-evaluate continuation at 48 h.
Norethindrate acetate: 5–10 mg every 4 h. (up to 80 mg day^{-1})
Non-hormonal therapy (used in consultation with Haematology)
Antifibrinolytic agents
≤12 years: Oral or IV aminocaproic acid 50–100 mg kg^{-1} per dose every 4–6 h (max: 24 g day^{-1})
≥12 years: IV tranexamic acid 10 mg kg^{-1} (maximum 600 mg $dose^{-1}$) 8 h until bleeding is stopped without the need for tapering
Packed red cells or IV iron
Select cases
IV desmopressin (DDAVP) in patients with a diagnosis of VWD or platelet function disorder and, in the case of VWD- a documented response to desmopressin > 75%, VWF level once daily over 2–3 days
Clotting factor replacement with an established clotting factor deficiency
Balloon tamponade (as a temporary measure to limit bleeding while further surgical methods are being sought) or medical therapy is being instituted
Second line
50 μg ethinyl oestradiol containing combination OCP
Dilatation and curettage – rarely indicated in adolescents, but maybe be accompanied by hysteroscopy if a local pathology suspected (e.g. polyp)

Table 3. Management of acute heavy menstrual bleeding on an outpatient basis or tapering treatment once patient stabilized.

Medication	Tapering regimens
50 μg ethinyl oestradiol containing combination OC	Every 6 h until bleeding stops, then decrease to every 8 h for 2 days and up to 7 days, then every 12 h for 2 days and up to 7 days, then daily thereafter. If transitioning from IV premarin, may decrease to 50 μg pill every 6 h to every 8 h, then as above
30–35 μg ethinyl oestradiol combination contraceptive pill	Every 6 h until bleeding stops, then decrease to every 8 h for 3 days (and up to 7 days) then every 12 for 2 days (and up to 7 days), then daily thereafter
Norethindrone acetate	510 mg every 4 h orally until bleeding stops, then every 6 h for 4 days, then every 8 h for 3 days, then every 12 h for 2 days to 2 weeks, then daily afterwards.
Consideration of antifibrinolytic therapy (Refractory cases or those with an established bleeding disorder)	≤12 years: Aminocaproic acid 50–100 mg kg^{-1}per dose PO every 4–6 h for 5–7 days (maximum daily dose: 24 g day^{-1}) ≥12 years: Tranexamic acid (650 mg tablets) (Lysteda) 1300 mg three times daily for 3–5 days (maximum daily dose: 3900 mg day)

Iron deficiency anaemia

An important aspect of managing women with HMB and improving quality of life involves replenishing iron stores [46]. Oral iron salts are a low cost option for iron supplementation but often cause gastrointestinal (GI) side effects. In our experience, adolescents are non-compliant with oral iron if they experience abdominal pain and constipation. We prefer oral iron polysaccharide formulations for uncomplicated iron deficiency, as they may be better tolerated with minimal GI side effects and offer a convenient once a day dosing. Intravenous iron (IV) is a very attractive option for young women with HMB, who are non-compliant or experience GI side effects from oral iron formulations that often compound menstrual cramps. We collaborated with iron experts within our division in devising protocols for IV iron (Table 3). We take a combined decision with the patient and family regarding either continuation of oral iron therapy or treating with IV iron.

Assessment of patient and clinic outcomes

Follow-up management. Routine follow-up is scheduled at 6–8 weekly intervals after the first evaluation and includes repeat PBAC, medication review and coagulation testing as appropriate for that visit. Assessment for an underlying aetiology for HMB proceeds in a step-wise manner. Patients continue to be seen in the clinic till either a diagnosis of bleeding disorder is established or excluded. Once a diagnosis of a bleeding disorder is established, HMB controlled, and iron stores replenished or anaemia corrected, patients are seen every 6–12 months. As each patient's presentation and course is unique, we provide each patient with an individualized 'period-plan'. This includes instructions on the steps to undertake in case of breakthrough bleeding, when and how to escalate therapy, initiate non-hormonal adjuvant therapy and when to call the clinic.

Outcomes assessment. Managing the psychological and social aspects of living with a blood disorder, timely diagnosis and optimal treatment are the primary goals of our programme. Surveillance and analysis of health outcomes such as quality of life, fatigue, healthcare utilization, disease surrogates and economic impact of HMB in adolescents are integrated into our comprehensive, multidisciplinary care model for clinical care but also through observational and translational research initiatives. Proceeding forward, we plan to use this information critically to identify the changing needs of the patients, identifying problems that need to be addressed and to document the effect that our healthcare delivery model has made.

Collaborative clinical, translational and laboratory research

The application of innovative management approaches including surrogates of disease in a multidisciplinary healthcare model represent continuous strides towards efficient translation for patient benefit and should ideally involve research. This has the potential to generate novel data that ultimately serves to improve patient outcomes. This led us to initiate, at the outset, a prospective cohort study and a multinational, multicentre registry to study the frequency and long-term outcomes of bleeding disorders in young women with HMB utilizing a comprehensive testing and management approach. This registry, endorsed by the ISTH, is open to accrual and can be accessed at http://www.isth.org/members/group.aspx?id=100375.

Foundation for women & girls with blood disorders

The Foundation for Women & Girls with Blood Disorders (FWGBD) is a non-profit organization that seeks to ensure that all women and girls with blood disorders are correctly diagnosed, optimally treated and managed at every life stage. FWGBD has been effectively gaining recognition and momentum as a key resource for providing education, guidance and expertise to physicians and other healthcare providers in the care of women and girls with blood disorders. The YWBD Clinic at UT Southwestern is part of the

Table 4. Prompt diagnosis of young women with HMB and previously unrecognized bleeding disorders at our centre.

	Historical cohort of women with type 1 VWD surveyed by CDC	Our comprehensive model (July 2014–June 2015)
No. of women	75	72
Age (years)	40 (18–70)	15 (9–20)
Average number of bleeding symptoms reported	6 (1–19)	2 (1–4)
Most common symptom	HMB (84%)	HMB (100%)
Number diagnosed	75*	21
Time to diagnosis	16 years (0–39 years)	4 months (1–9 months)
Perception of satisfactory care at HTC	94.6%	98.6%†

VWD, von Willebrand disease; CDC, Center of Disease Control.
*By design, all women included in this survey were a subset of a sample of women with type 1 VWD receiving care in haemophilia treatment centres (HTCs). Forty-six HTCs were represented.
†Information obtained by a survey.

FWGBD learning action network (LAN) (other LAN members can be accessed through this link: http://www.fwgbd.org/wgbd-learning-action-network-lan/current-lan-members). Convened predominantly on a cost-effective web platform, the FWGBD LAN is an exchange of key information and best practices in the care of women with blood disorders. FWGBD identified the LAN as the mechanism to assist HTCs in the establishment and implementation of a quality clinic. FWGBD LAN participants further benefit from input and guidance by the FWGBD cadre of experts—the board, medical advisors and the emerging experts on FWGBD's Education Council, who are newer-generation haematologists and gynaecologists who will be leading the care, practice improvement, education and research of women/girls with blood disorders in the not-too-distant future.

Conclusions

Menstrual disorders are no longer conditions that women keep in the 'dark'; an increasing number of women or parents of such young women seek medical attention [47]. There is an existing need to offer comprehensive care to women with HMB and blood disorders. This need is likely going to increase over the next decade in view of the growing awareness among women *and* healthcare providers of such disorders and their frequent occurrence. While the long-term follow-up in assessing the ultimate success of this model is under ongoing data accrual and assessment, our YWBD programme *appears* to be successful in delivering optimal care to young women affected with HMB and concomitant blood disorders. Table 4 provides a glimpse of effective care delivery and prompt diagnosis of an undiagnosed bleeding disorder in adolescents with HMB through our model compared with a historical cohort of women with VWD from 46 HTCs surveyed by the CDC[13].

Future directions

Our current short-term efforts are focused on including a genetic counsellor and a dedicated social worker as multidisciplinary team members. In the long-term, we envision taking this programme forward and making it into a *Women and Girls with Blood Disorders Centre of Excellence* by incorporating an adult haematologist with expertise in haemostasis thrombosis, who will facilitate the comprehensive care that young women receive currently in the combined programme without the need to be transitioned to an adult haematologist and to include specialized care and follow-up when pregnant. Such a health delivery model would include all the players we described herein and a similar programmatic approach in creating a 'medical home' for young and older women with a suspected and established bleeding disorder.

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Author contributions

A. Zia wrote and all authors edited and revised the manuscript. P. Kouides provided expert opinion, modified the testing and management algorithm and critically revised the manuscript.

Disclosures

The authors stated that they had no interests which might be perceived as posing a conflict or bias.

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