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## Complex family planning and pediatric hematology oncology integrated clinic for young people with blood disorders and heavy or abnormal menstrual bleeding

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### Abstract

**Objectives:** To describe practice patterns of an integrated complex family planning-pediatric hematology oncology clinic for patients with blood disorders

**Study design:** We retrospectively evaluated the outcomes of patients who had an initial consultation for blood disorders impacting menstrual bleeding in an integrated complex family planning-pediatric hematology oncology clinic from October 2015 to September 2020. We reviewed all charts to extract medical and gynecologic history, blood disorder diagnosis, hormonal treatment prior to and following initial consultation, subsequent visits to the integrated clinic, and hormonal treatment up to 24 months after initial consultation.

**Results:** We saw 47 patients; their most common blood disorder diagnosis was protein defect (14/47, 30%). Most patients (30/47, 64%) were not using any hormonal treatment prior to their initial consultation. After the initial consultation, 26 (55%) elected to start, change, or discontinue hormonal treatment for abnormal menstrual bleeding, the most common treatment being combined hormonal contraception (CHC, 22/47, 47%), alone or as dual therapy. Over the study duration, 36 patients (77%) initiated, changed, or discontinued their hormone treatment, 22 (61%) of whom changed their treatment plan more than once. CHC usage decreased from 19/47 (40%) to 8/37 (22%) and hormonal device usage, particularly the implant, increased from 9/47 (19%) to 11/37 (30%) over the 24 months from initial consultation.

**Conclusion:** Most patients in an integrated complex family planning-pediatric hematology oncology clinic will change their menstrual bleeding hormone treatment with initial consultation,

although management may require multiple changes. The most common treatment 24 months following the initial consultation was hormonal devices.

**Implications:** Patients with blood disorders affecting menstrual bleeding have complex needs that could be addressed by an integrated complex family planning-pediatric hematology oncology clinic. Most patients require multiple changes in treatment to achieve adequate control of their bleeding, and patients were more likely to choose hormonal devices for management over time.

## 1. Introduction

Nearly 40% of menstruating adolescents complain of heavy menstrual bleeding that interferes with their quality of life.[1] Heavy bleeding at menarche may signal an underlying bleeding disorder, which is identified in 20–33% of adolescents presenting for evaluation for heavy menstrual bleeding and 33% of those hospitalized for heavy menstrual bleeding. [2–4] For those already diagnosed with an inherited bleeding disorder, 75–80% report heavy menses as their most common symptom of their condition,[5,6] including passing clots and “flooding” through clothes and sheets.[7] Adolescents report a poorer quality of life due to their heavy menstrual bleeding, which limits participation in school, sports, and social activities.[2,8] More than half of those with heavy menstrual bleeding will miss school during their menstrual bleeding, which is concerning when chronic absenteeism (missing 10% or more of the academic year for any reason) is associated with lower standardized test scores in math and language and delayed or lower graduation rates.[8,9] Treatments, including hormonal treatments and hemostatic agents alone or in combination, can improve menstrual blood loss and quality of life scores.[10] The American College of Obstetricians and Gynecologists and the American Society of Hematologists recommend gynecologists and hematologists work in coordination to manage adolescents with heavy or abnormal menstrual bleeding that may be associated with a bleeding disorder, ideally at a multidisciplinary clinic site.[11,12]

We addressed this recommendation in our institution by establishing the Women and Girls with Blood Disorders (WGBD) clinic, a partnership between pediatric hematologists-oncologists and complex family planning specialists that is housed in the pediatric hematology-oncology offices. Complex family planning specialists are gynecologic subspecialists with “advanced knowledge in the areas of preventative, diagnostic, and therapeutic procedures necessary for optimal reproductive health.”[13] In this monthly clinic, a complex family planning-trained gynecologist sees patients jointly with the hematologist-oncologist so that patients experience one visit. The Foundation for Women & Girls with Blood Disorders lists 41 designated women/girls bleeding disorder clinics in the United States, of which 22 report offering in-clinic gynecology services without mention of complex family planning specialists.[14] We aimed to describe the patients seen in our clinic, their choice of therapy, and outcomes.

## 2. Materials and Methods

We reviewed the electronic medical records of patients who were referred to the UC Davis WGBD clinic at the University of California, Davis Medical Center from October 2015 to September 2020. We included patients who were post-menarchal and seen by

both a hematologist-oncologist and a complex family planning specialist on the same day. We defined heavy or abnormal menstrual bleeding solely by patient perception, without objective criteria. We collected demographic information, gynecologic history, details of their hematologic or oncologic issue, bleeding patterns, medical history and medications that may alter therapy choices, and therapy counseling outcomes for the first visit. Subsequent WGBD clinic visits were reviewed for hormonal medications and changes in therapy through an end date of February 1, 2021. We also documented any treatment changes initiated outside the WGBD clinic, such as self-discontinuation or changes made in outpatient settings outside the integrated clinic. For the time intervals of 6, 12, 18 and 24 months following initial consultation, we designated the hormonal treatment a patient was using as the recorded treatment in the electronic medical record that was closest to the time point of interest. Any patients who had records within 3 months of time interval but did not have any treatment recorded was categorized as “not recorded.” We defined patients as “lost to follow-up” if the patient did not have any further encounter with the health system as recorded in the electronic medical records. All data were derived from medical records; we did not attempt to contact clinicians or patients for missing information. Our institutional review board deemed this study exempt. We analyzed data using SAS 9.2 (SAS Institute Inc, Cary, NC, USA).

### 3. Results

Of the 59 patients referred to the UC Davis WGBD clinic from October 2015 to September 2020, 47 met inclusion criteria. Four patients did not meet inclusion criteria due to premenarchal status, three did not visit the integrated clinic during the study period, and five met only the complex family planning specialist during their initial consultation. The demographics of the included patients are listed in Table 1. The most common blood disorder diagnosis in our patient population was protein defect (14/47, 30%), which includes hemophilia A, von Willebrand disease, and other clotting factor deficiencies. Sixteen (34%) were using hemostatic agents such as aminocaproic acid (8/16, 50%) and desmopressin acetate (7/16, 44%). Most patients (25/47, 53%) had one visit in the integrated clinic seeing both specialists with no further in-person follow-up in the integrated clinic.

The most common treatment attempted among patients prior to their initial consultation was combined oral contraceptives (22/47, 47%) followed by depot medroxyprogesterone (DMPA, 10/47, 21%), but at the time of the initial consultation, the majority (30/47, 64%) were not on any hormonal treatment. Nine (19%) had contraindications to estrogen hormonal treatments (9/47, 19%) and few were sexually active (6/47, 13%). At the end of their initial consultation, 26 (55%) elected to start, change, or discontinue hormonal treatment for heavy or abnormal menstrual bleeding. The most frequent treatment following the initial consultation was combined hormonal contraceptives (CHC, including estrogen-containing pills, transdermal patch, and vaginal ring, 22/47, 47%), alone or as dual therapy with a progestin-only method such as DMPA, etonogestrel subdermal implant, or levonorgestrel intrauterine system (LNG IUS), followed by DMPA alone (6/47, 13%).

From the time of their initial consultation in WGBD to the end of the study period, 36 patients (77%) initiated, changed, or discontinued their hormone treatment, of which 31

(86%) did through encounters at the WGBD clinic. Of the 36 patients, 22 (61%) changed their treatment plan more than once, with one changing treatment 4 times. Reasons for treatment change included insufficient bleeding improvement, breakthrough bleeding or other side effects, desire for a lower-maintenance hormonal treatment, or new treatment contraindications.

We also examined hormonal treatments at 6, 12, 18, and 24 months after the initial consultation as recorded in the electronic medical record (Table 2). CHC use decreased to 8 of 37 patients (21.6%) at 24 months from initial consultation (Figure 1), with no use of dual therapy by 18 months. However, hormonal device usage increased with time, with 11 patients using devices at 24 months (11/37, 30%).

#### 4. Discussion

Our Women and Girls with Blood Disorders joint clinic with pediatric hematologists-oncologists and complex family planning specialists sees patients with diverse blood disorders, with a third categorized as protein defects. Although most consultations did not lead to subsequent visits, those who had subsequent visits continued to have changes to their hormone treatments 2–4 times during the study period. Interestingly, more patients used hormonal devices compared to combined hormonal contraception at 24 months following initial consultation.

The proportion of blood disorders such as protein defects and platelet function disorders varies among clinics and networks who have published their experiences, likely reflecting geographic differences in diagnostic practices or disorder prevalence.[15–18] Among girls with inherited platelet function disorders in a clinic at the University of Michigan, heavy menstrual bleeding was difficult to control despite treatment adjustments,[19] which reflects our clinical experience as well. These studies have focused on prevalence, diagnosis, and treatment of heavy menstrual bleeding in patients with blood disorders, with limited use of hormone therapy other than oral contraception and DMPA.[16,17,19,20] However, the LNG IUS is approved by the U.S. Food and Drug Administration for the treatment of heavy menstrual bleeding[21] and other studies have described menstrual bleeding improvement with etonogestrel implant.[22,23] Our patients tended toward hormonal devices such as implant and LNG IUS more frequently than CHC by 24 months following initial consultation, which suggests that patients are willing to accept these devices as treatment options if offered. The frequency of device use may be associated with our integrated clinic's access to complex family planning specialists who are experienced with implant and IUS counseling and insertion in medically complex and young patients.

Limitations of our study include its retrospective nature, with data collection limited to the chart review of a small number of patients. We could not estimate rates of treatment change by reason since reasons were inconsistently documented. We did not have data on patients who may have sought subsequent care outside our institution, so we may not have captured additional changes in treatment options. Although we defined heavy or abnormal menstrual bleeding by patient complaint rather than by objective measures, we feel using this patient-centered definition is most reflective of real-life practice patterns and thus a

strength of this study. Another strength of this study is the duration of follow-up of up to two years.

Our study describes the practice patterns of an integrated clinic involving complex family planning specialists for patients with blood disorders and heavy or abnormal menstrual bleeding, which demonstrates a higher utilization of hormonal devices for treatment of heavy or abnormal menstrual bleeding than described in other studies.[17,19,20] The Complex Family Planning fellowship recently received approval as an obstetrics and gynecology subspecialty from the Accreditation Council for Graduate Medical Education (ACGME),[13] but has graduated over 400 fellows since 1991 whose expertise includes counseling and use of all available contraceptive methods for patients with complex medical or psychosocial conditions.[24] Since many contraceptive methods also have non-contraceptive benefits like improvement of menstrual bleeding, our descriptive study supports the involvement of these specialists in integrated clinics so that medically complex patients may have equitable access to these treatments by skilled providers.

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**Table 1:**

Characteristics of patients with heavy or abnormal menstrual bleeding seen at an integrated Complex Family Planning-Pediatric Hematology Oncology clinic for Women and Girls with Blood Disorders (WGBD) at the University of California, Davis Medical Center for an initial consultation from October 2015 to September 2020.

Characteristic	N=47
Age at initial visit	16 y (10–25y)
Number of encounters in WGBD	
1 (initial consultation)	25 (53)
2	10 (21)
3	4 (9)
4	3 (6)
5	3 (6)
6	2 (4)
Race	
White	23 (49)
Black	4 (9)
Asian	1 (2)
Other/Multiracial	14 (30)
Unidentified	5 (11)
Ethnicity	
Hispanic	13 (28)
Non-Hispanic	30 (64)
Unknown	4 (9)
Insurance	
Public	21 (45)
Private	26 (55)
Nulligravid	46 (98)
Body Mass Index	
Underweight	3 (6)
Normal weight	25 (53)
Overweight	9 (19)
Obese	10 (21)
Blood disorder categories	
Protein defects *	16 (34)
Platelet disorders	6 (13)
Cancer	6 (13)
Thrombotic disease on therapeutic anticoagulation	4 (9)
Other hematologic (hereditary spherocytosis, pyruvate kinase deficiency)	3 (6)
Laboratory abnormalities not meeting diagnostic criteria for blood disorder	3 (6)
No hematologic diagnosis recorded	9 (19)
History of iron supplementation	16 (34)



Characteristic	N=47
History of blood transfusion	12 (26)
Contraindication to estrogen-containing contraception[25]	9 (19)
Self-reported irregular menstrual cycle	21 (45)
Self-reported history of heavy menstrual flow	39 (83)
Self-reported moderate to severe dysmenorrhea	27 (57)

Data expressed in median (range) or number (%). Percentages may not add to 100% due to rounding.

\* Protein defects include hemophilia A, von Willebrand disease, and other clotting factor deficiencies.

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**Table 2:**

Hormonal treatments recorded in electronic medical records of patients with heavy or abnormal menstrual bleeding initially seen at an integrated Complex Family Planning-Pediatric Hematology Oncology clinic for Women and Girls with Blood Disorders (WGBD) at the University of California, Davis Medical Center at 6-month intervals from initial consultation to 24 months.

	<b>0 mo</b>	<b>6 mo</b>	<b>12 mo</b>	<b>18 mo</b>	<b>24 mo</b>
	<b>N=47</b>	<b>n=45</b>	<b>n=42</b>	<b>n=39</b>	<b>n=37</b>
None	11 (23.4)	12 (26.6)	13 (31)	11 (28.2)	11 (29.7)
CHC	19 (40.4)	15 (33.3)	12 (28.6)	11 (28.2)	8 (21.6)
POP	2 (4.3)	2 (4.4)	1 (2.4)	1 (2.6)	1 (2.7)
DMPA	6 (12.7)	5 (11.1)	4 (9.5)	4 (10.2)	4 (10.8)
Implant	4 (8.5)	2 (4.4)	4 (9.5)	6 (15.4)	6 (16.2)
LNG-IUS	2 (4.3)	4 (8.9)	4 (9.5)	4 (10.3)	5 (13.5)
DMPA + CHC	0	1 (2.2)	0	0	0
Implant + CHC	1 (2.1)	1 (2.2)	1 (2.4)	0	0
LNG-IUS + CHC	2 (4.3)	1 (2.2)	1 (2.4)	0	0
Not recorded	0	2 (4.4)	2 (4.8)	2 (5.1)	2 (5.4)

Data expressed in number (%). Percentages may not add to 100% due to rounding. CHC, combined hormonal contraception; POP, progestin-only pill; DMPA, depot medroxyprogesterone; LNG-IUS, levonorgestrel intrauterine system.