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Providing Young Women with Credible Health Information about Bleeding Disorders

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Abstract

Background—Approximately 1% of U.S. women may have an undiagnosed bleeding disorder, which can diminish quality of life and lead to life-threatening complications during menstruation, childbirth, and surgery.

Purpose—To understand young women's knowledge, attitudes, and perceptions about bleeding disorders and determine the preferred messaging strategy (e.g., gain- versus loss-framed messages) for presenting information.

Methods—In September 2010, a web-assisted personal interview of women aged 18–25 years was conducted. Preliminary analyses were conducted in 2011 with final analyses in 2013. In total, 1,243 women participated. Knowledge of blood disorders was tabulated for these respondents. Menstrual experiences of women at risk for a bleeding disorder were compared with those not at risk using chi-square analyses. Perceived influence of gain- versus loss-framed messages also was compared.

Results—Participants knew that a bleeding disorder is a condition in which bleeding takes a long time to stop (77%) or blood does not clot (66%). Of the women, 57% incorrectly thought that a bleeding disorder is characterized by thin blood; many were unsure if bleeding disorders involve blood types, not getting a period, or mother and fetus having a different blood type. Women at risk for a bleeding disorder were significantly more likely to report that menstruation interfered with daily activities (36% vs 9%); physical or sports activities (46% vs 21%); social activities (29% vs 7%); and school or work activities (20% vs 9%) than women not at risk. Gain-framed messages were significantly more likely to influence women's decisions to seek medical care than parallel loss-framed messages. Findings suggest that the most influential messages focus on knowing effective treatment is available (86% gain-framed vs 77% loss-framed); preventing pregnancy complications (79% gain- vs 71% loss-framed); and maintaining typical daily activities during menstrual periods.

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Conclusions—Lack of information about bleeding disorders is a serious public health concern. Health communications focused on gain-framed statements might encourage symptomatic young women to seek diagnosis and treatment. These findings and corresponding recommendations align with Healthy People 2020 and with CDC's goal of working to promote the health, safety, and quality of life of women at every life stage.

Introduction

The term *bleeding disorders* refers to a group of conditions in which abnormalities in hemostasis can lead to spontaneous or prolonged bleeding.[1] Hemophilia, an X-linked genetic blood disorder that affects boys and men primarily, is the most well known. Women who carry one copy of the abnormal gene also can experience heavy bleeding symptoms and have mild hemophilia.[2] Other bleeding disorders, such as von Willebrand disease (VWD), are a result of inherited abnormalities on autosomal chromosomes and can affect both men and women.[3] Symptoms resulting from these disorders can be more severe for women because of their associated effects on menstruation, pregnancy, and childbirth.[2,4,5]

Approximately 1% or as many as 2 million women in the U.S. might have an undiagnosed bleeding disorder,[6] yet most of these disorders remain undetected for years, and many are never diagnosed despite serious gynecologic and obstetric challenges experienced by these women throughout their lives. A 2009 CDC study[7] showed that the prevalence of VWD or other blood factor deficiencies among women with menorrhagia (excessive menstrual bleeding) was much higher than U.S. gynecologists generally perceived it to be. A systematic review[8] of published studies estimated that 5%–24% of women with menorrhagia might have undiagnosed VWD.

Women with bleeding disorders are at increased risk for complications such as anemia, bleeding during pregnancy, and postpartum hemorrhage and may undergo unnecessary hysterectomy and other uterine surgeries that can lead to life-threatening complications.[4,9] Furthermore, undiagnosed bleeding disorders affect women's quality of life and well-being by limiting participation in education, employment, social, and leisure activities.[9,10] Studies[2,4,10] have shown that complications can be decreased or prevented and quality of life can be improved by early diagnosis and appropriate management.

Since 1996, CDC has been committed to collaborative research to determine the prevalence of bleeding disorders, assess provider awareness of these conditions, and evaluate treatment and management options to improve care for women with bleeding disorders.[11] Likewise, the National Hemophilia Foundation (NHF) has been working to raise awareness that women are affected by bleeding disorders.

In 2009, CDC and NHF entered into a cooperative agreement to improve the health of people with bleeding disorders through health education. Specific program activities focused on increasing awareness of bleeding disorders among undiagnosed women and health professionals. These activities are consistent with Healthy People 2020 objectives Blood Disorders and Blood Safety (BDBS)-14 and BDBS-15, which focus on appropriate referral

of women who are symptomatic for timely and accurate diagnosis and treatment of bleeding disorders.[12]

To better understand young women's knowledge, attitudes, and perceptions about bleeding disorders, the NHF commissioned an online assessment conducted by Harris Interactive in 2010 to (1) assess women's knowledge about bleeding disorders; (2) identify how women aged 18–25 years perceived menstrual problems within their personal, self-care, work/school, home, and social domains; (3) determine if young women were more likely to take action—such as seeking health care for heavy bleeding—because of the perceived benefits of taking action or because of the negative consequences of not taking action; and (4) determine the best strategies for developing and presenting key messages about menorrhagia and bleeding disorders to young women aged 18–25 years.

Methods

In spring 2010, the NHF convened a panel of experts from NHF, CDC, and Harris Interactive to develop a survey instrument to assess the knowledge, attitudes, health behaviors, and menstrual experiences of young women. Over the course of 3 months, the group used an iterative process consisting of brainstorming activities and nominal group techniques to develop the survey instrument. Questions were developed to capture knowledge of menstruation and bleeding disorders; menstrual experiences within personal, self-care, work/school, home, and social contexts; health care–seeking behavior; preferred sources of health information; and demographic information.

After several rounds of review and revisions, items were finalized and agreed upon by the panel. In addition, the panel constructed a scenario about a young woman with symptoms of a bleeding disorder that was embedded in the survey and used to determine the preferred messaging strategy for presenting credible health information to young women. Owing to budget constraints, no formal pilot testing was done. However, members of the expert panel independently reviewed the questions and conducted a usability test before the survey was launched.

In September 2010, a national survey of women aged 18–25 years in the U.S. was conducted using a web-assisted personal interview. The survey was determined to be public health practice (non-research) by CDC on July 10, 2010. Therefore, an institutional review was not required. The survey was administered in English and took approximately 15 minutes to complete.

Respondents were selected from the Harris Poll Online (HPOL), a multimillion-member panel of cooperative online respondents. The panel has been used in other public health research studies.[13–18] An invitation with a link to the online survey was e-mailed to 59,124 female members of the HPOL. A total of 1,243 women aged 18–25 years participated in the survey, with an overall response rate of 4.8%. Of those participants, the responses of 1,239 were used in the study analyses; the responses of four participants were excluded from the analyses because they had never had a menstrual period.

Preliminary analyses were conducted in 2011 and final analyses were completed in 2013. Data were weighted, using a rim-weighting algorithm,[19] to be representative of the U.S. population of women aged 18–25 years. Variables used for weighting were region, age, education, household income, race and ethnicity, and a propensity score. Propensity score–matching methodology has a strong statistical lineage in situations of nonrandom assignment to groups.[19,20] The propensity score is used to correct for potential attitudinal and behavioral biases that can arise with the use of an online panel that cannot be corrected through weighting of demographic characteristics alone.

These potential biases are associated with panelists' nonrandom choices to be active online, join a panel, and respond to a particular survey. The propensity score is designed to measure differences related to the way respondents share and use information and participate in or engage with society, two key dimensions associated with their nonrandom choices. To validate this approach, Harris Interactive has conducted numerous parallel tests comparing results from online research with results from probability-based samples.[20]

After completing items about the symptoms of bleeding disorders and menstrual health, all respondents—with the exception of those diagnosed with a bleeding disorder—were presented a scenario about a young woman who had symptoms of a bleeding disorder (n=1,205). Respondents were assigned randomly to react to messages from either a gain-framed (n=603) or loss-framed (n=602) perspective.

The gain-framed messages stressed that positive results would be gained by taking action to seek treatment from a healthcare professional. The loss-framed messages focused on the negative consequences of not taking such action. Women were asked to rate, on a scale of 1 to 4 (1 being *not at all* and 4 being *a great deal*), how motivating a series of statements would be in influencing them to seek treatment from a healthcare professional if they experienced similar symptoms.

Using weights provided by Harris Interactive, distribution of responses was calculated using SAS, version 9.3. Chi-square statistics were calculated to assess associations between variables. Significance tests were reported for probabilities <0.05. Women were stratified into two categories: being at risk and not being at risk for a bleeding disorder. Those at risk were defined as either having periods lasting 8 days or longer, often or always bleeding through a pad or tampon in 1 hour or less, or often or always feeling a sense of flooding or gushing. These definitions are consistent with expert opinion as being predictive of bleeding disorders.[21,22]

Results

A total of 1,239 women aged 18–25 years participated in the survey. In the sample, 58% self-identified as white, 15% as black or African American, 15% as Hispanic, 8% as Asian or Pacific Islanders, and 5% as other (this survey did not use official Office of Management and Budget race and ethnicity categories to collect these data); 34% had completed high school and 45% had completed some college or had an associate degree; and 44% were

unemployed, whereas 38% were employed part-time. Each geographic region of the U.S. was represented in the sample (Table 1).

Knowledge of Bleeding Disorders

Women were asked to indicate whether seven statements about bleeding disorders were true or false. Approximately two thirds (66%) of participants correctly identified blood that does not clot as a medical condition associated with a bleeding disorder. Although most respondents (77%) knew that bleeding takes a long time to stop when a person has a bleeding disorder, nearly six in ten (57%) incorrectly believed that a bleeding disorder is a medical condition in which the blood is too thin, and a little over one third (35%) were unsure of the answer. Almost half (49%) were unsure if a bleeding disorder is a condition in which a woman does not get her period, and almost half (49%) were unsure whether it involves blood types. More than a quarter (27%) of respondents did not know that bleeding disorders are not contagious (Table 2).

Menstrual Experience

Although 6% of the surveyed young women had ever thought they might have a bleeding disorder, only 2% had ever received such a diagnosis. However, 23% of respondents reported one or more at-risk symptoms of a bleeding disorder. Those at risk were defined as having either periods lasting 8 days or longer, often or always bleeding through a pad or tampon in 1 hour or less, or often or always feeling a sense of flooding or gushing.

Of those displaying at-risk symptoms (*n*=282), 21% had periods that last 8 days or longer, 34% said they always or often bleed through a tampon or pad in 1 hour or less, and 71% said they always or often feel a sense of flooding or gushing. Compared with women not at risk for a bleeding disorder, women at risk reported that they endured significantly more stress during the heaviest days of their period ($p<0.0001$) and were significantly more likely to report that their period interfered with their everyday activities ($p<0.0001$), particularly physical activities or sports ($p<0.0001$) and attendance at work or school ($p<0.0001$) (Table 3). Among women at risk, 20% had sought medical treatment for heavy periods versus 12% of women who were not at risk ($p=0.0026$).

Messages to Motivate Young Women to Seek Care

After reading a scenario about a young woman with symptoms of a bleeding disorder, respondents were asked to rate a series of statements on their ability to motivate them to seek treatment if they experienced similar symptoms. In other words, would young women be prompted to seek care because a potential negative health outcome would occur if they did not (loss-framed)? Or, would they be more likely to seek care because a potential positive health gain would occur if they did (gain-framed)?

Overall, gain-framed message statements were more influential among respondents in the decision to seek treatment than were those that were loss-framed. Ten parallel message statements were presented in both gain- and loss-framed wording. For six of the statements, the percentage of respondents who indicated the gain-framed message would have a moderate or great amount of influence was significantly higher (p 0.01) than for the loss-

framed statements. None of the loss-framed statements received a higher percentage of respondents, indicating a moderate or great amount of influence (Table 4).

Message statements in which gain-framed wording was more influential than loss-framed wording included the following: "…knowing there was an effective treatment available" (86% gain vs 77% loss); "…get my heavy bleeding under control so I would not be at risk for pregnancy complications" (79% gain vs 71% loss); "…go to school or work on days I have my period" (83% gain vs 77% loss); "…get my heavy bleeding under control so I would not be at risk for a miscarriage in the future" (77% gain vs 67% loss); "…have dental work without bleeding" (65% gain vs 54% loss); and "…not have to buy so many pads and tampons" (57% gain vs 48% loss) (Table 4).

Preferred Channel for Receiving Information

Respondents were asked to identify their preferred channels for receiving information about general health, women's health, menstruation, heavy periods, and bleeding disorders. Respondents also were asked to select their top two choices from a list of traditional (e.g., print media, television, radio) and digital media (e.g., webcasts/webinars, e-mail, social media, blogs/discussion boards) and were provided an option to select *none of these*. Respondents increasingly chose *none of these* as a preferred channel of receiving health information related to menstruation (48%); heavy periods (51%); and bleeding disorders (51%) compared with their selections regarding general health (37%) and women's health information (38%).

Discussion

The results of this study suggest that lack of information about bleeding disorders is a problem because many women were unsure about the definition. Lack of knowledge also was evident in that fewer than half of respondents recognized that periods lasting 8 days or longer should be cause for concern. Women at risk perceived their stress to be higher during the heaviest days of their periods and believed that heavy bleeding interfered with activities of daily living, which in turn affected quality of life. Educating women regarding symptoms, particularly soaking through a pad or tampon in 1 hour or less (which they might have considered normal), could prompt them to initiate a conversation with a healthcare professional.

Health messages can be worded based on the perceived behavioral gains or losses of taking actions that affect health. This approach is referred to in the health communications literature as gain- or loss-framed messaging.[23] Some studies[24,25] have shown that gain-framed messages are effective in situations in which the risk associated with the health behavior is low. Conversely, when the risk is high, loss-framed messages might be more effective.

Meta-analyses[26,27] of health message framing indicate that gain-framed messages might be more persuasive than loss-framed messages when promoting prevention-oriented behaviors. Jonathan van't Riet and colleagues[28] postulate that message framing might have implications for increasing acceptance of health-promoting messages. This is because

"information acceptance might be of critical importance" and "people seeking information on the Internet are most likely to select information that seems relevant, interesting, and trustworthy."[28]

Data from this study suggest that messages to influence women who have symptoms of a bleeding disorder to seek health care should focus on gain-framed statements. The messages that survey respondents found most compelling were those that focused on knowing that there is treatment available, that care for the disorder can prevent pregnancy complications and miscarriages, and that care could result in a work and school life that is not disrupted by heavy bleeding. The NHF is using the findings from this study to revise existing loss-framed health communication materials with new gain-framed messaging.

Respondents were asked to select their preferred channel for receiving health information from a list of traditional and digital media. Roughly half indicated that none of the channels listed were a preferred way to receive information about menstruation, heavy periods, and bleeding disorders. Perhaps, as health topics became more personal, women were more likely to select "none of the above" because they may prefer to receive information from individualized communication channels such as healthcare providers, family members, or friends. Unfortunately, these response choices were not included for this question. Further study is needed to determine the best dissemination channels for presenting key messages about these topics to young women.

Limitations

The use of online polls has become increasingly valuable in finding out what people think and how they behave. However, the use of online polling as a methodology has several limitations that might affect interpretation of our results. This study's sample was selected from the HPOL panel and completion was voluntary; therefore, self-selection bias was a limitation. Surveys that rely on self-report might be subject to intentional deception, poor recall, or misunderstanding of the questions. Women who are willing to disclose information about their menstrual experiences might differ from those who are not. Respondents reported their personal experiences and responses were not verified independently.

Finally, the low response rate is of concern and limits the generalizability of these findings. Owing to resource constraints, the authors were unable to pilot test the survey or engage the survey contractor in additional follow-up activities. Despite these limitations, the findings have provided valuable information that can be used to develop health communication strategies that will influence young women to seek care if they have symptoms suggestive of a bleeding disorder.

Conclusions

Lack of information about bleeding disorders among young women is a serious public health concern. Barriers identified through this study, such as lack of knowledge about symptoms and ineffective messaging, may contribute to as many as 2 million women in the U.S. with an undiagnosed bleeding disorder.[6] A public health framework that includes evidence-based health communications focused on gain-framed statements could influence symptomatic young women to seek diagnosis and treatment. These findings and corresponding

recommendations align with Healthy People 2020's national health objectives[12] and CDC's health protection goal for women—working to promote the health, safety, and quality of life of women at every life stage.[29]

Acknowledgments

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Table 1

Demographic characteristics of respondents (n=1,239)

Characteristic	%[a]
Race [b]	
White	58
Black or African American	15
Asian or Pacific Islander	8
Other race	5
Hispanic	15
Education	
Less than 12th grade	4
Completed high school	34
Some college or associate degree	45
Completed college	16
Advanced degree	<1
Region	
East	22
Midwest	23
South	31
West	25
Employment	
Full-time	17
Part-time	38
Unemployed	44

[a]Percentages may not sum to 100 because of rounding error.

[b]This survey did not use official Office of Management and Budget race and ethnicity categories to collect these data.

Table 2

Knowledge of bleeding disorders among women aged 18–25 (*n*=1,239)

Young women's beliefs on bleeding disorders	True, %	False, %	Not sure, %
A bleeding disorder is a medical condition…			
in which it takes a long time for bleeding to stop.[a]	77	1	22
in which one's blood does not clot.[a]	66	6	28
in which the blood is too thin.	57	9	35
that involves blood types.	17	32	50
in which a woman does not get her period.	15	36	49
in which a mother and fetus have different blood types.	9	42	49
that is contagious.	3	73	24

[a] Indicates that the statement is true.

Table 3

Menstrual experience of young women at risk for a bleeding disorder vs. not at risk[a]

Menstrual experience	Moderate/great amount of influence, %	
	At risk (*n*=282)	Not at risk (*n*=957)
On the heaviest days of your period, how often does your period interfere with your daily activities?	**36**	**9**
On the heaviest days of your period, how often does your period interfere with your sexual activities?	49	47
On the heaviest days of your period, how often does your period interfere with your physical or sports activities?	**46**	**21**
On the heaviest days of your period, how often does your period interfere with your social activities?	**29**	**7**
On the heaviest days of your period, how often does your period interfere with your school or work activities?	**20**	**9**

Note: Boldface indicates statistical significance (*p*<0.0001).

[a]We defined those at risk as having periods lasting 8 days or longer *or* often or always bleeding through a pad or tampon in an hour or less *or* often or always feeling a sense of flooding or gushing.

Table 4

Perceived influence of gain-framed versus loss-framed messages

Messages	Moderate/great amount of influence, %	
	Gain-framed (*n*=603)	Loss-framed (*n*=602)
Knowing there was an effective treatment available	**86**	**77**
Through treatment, I could get my heavy bleeding under control so I would not be at risk for pregnancy complications	**79**	**71**
Being able to go to school or work on days I have my period	**83**	**77**
Through treatment, I could get my heavy bleeding under control so I would not be at risk for a miscarriage in the future	**77**	**67**
Being able to have surgery without worrying about bleeding heavily	70	70
Being able to plan social activities on days I have my period	76	74
I would be able to be more active on the days I have my period	73	72
Being able to have sexual activity whenever I want	55	52
I would be able to have dental work without bleeding	**65**	**54**
I would save money and not have to buy so many pads and tampons	**57**	**48**

Note: Boldface indicates statistical significance (*p* 0.01).