

Heavy menstrual bleeding affects quality of life in adolescents

El sangrado menstrual excesivo afecta la calidad de vida en adolescentes

Romina Torres^a, Claudia Zajer^b, Marcela Menéndez^b, María José Canessa^b,
Jaime Cerda^c, María Angélica Wietstruck^d, Pamela Zúñiga^d

^aDepartment of Pediatrics. Pontificia Universidad Católica de Chile. Pediatrician

^bDepartment of Gynecology and obstetrics. Pontificia Universidad Católica de Chile. Childhood and youth Gynecologist

^cDepartment of Public health. Pontificia Universidad Católica de Chile. Pediatrician

^dDepartment of Pediatrics Pediatric Department Pontificia Universidad Católica de Chile. Hemato Oncology physician

Received: 18-03-2017; Accepted: 04-07-2017

Abstract

Introduction: Heavy menstrual bleeding (HMB) occurs in 37% of adolescents and compromise their quality of life. **Objective:** To measure the magnitude of the impact of the SME on the quality of life in adolescents. **Patients and Method:** We interviewed adolescents diagnosed with HMB between 10 and 18 years old and one of their guardians. PedsQL 4.0 generic core scale was applied to measure quality of life, its Proxy PedsQL 4.0 version was applied to the guardian and 3 more questions to adolescents about limitation of daily activities. The concordance between the guardian's perception of the adolescent quality of life and the adolescent's perception was evaluated with the Bland and Altman graph. **Results:** 46 adolescents and guardians were evaluated. The total average PedsQL 4.0 score for adolescents was 64.48 (SD 14.54), with a range of 18.48 to 88.04 with a greater involvement in the emotional dimension. 50% of adolescents missed school, 80.4% physical education and 65.2% outdoor activities or parties. There was no agreement between the perception of the girls and guardians. **Conclusions:** We evidence a deterioration in the quality of life of the surveyed adolescents, being the emotional dimension most affected. The performance in the questionnaire was also lower than in samples of chronic diseases published with this same tool.

Keywords:

Menstruation,
menometrorrhagia,
heavy menstrual
bleeding,
adolescents,
quality of life

Correspondence:
Pamela Zúñiga Contreras
pzuniga@med.puc.cl

Introduction

Menstruation is a physiological process which marks the woman reproductive potential¹. Initially, menstrual cycles tend to be anovulatory and may produce menometrorrhagia, a term replaced in 2011 by heavy menstrual bleeding (HMB)².

HMB is defined as the loss of menstrual blood more than 80 ml/cycle, change of sanitary products every 2 hours, or a duration longer than 7 days³. In 2007, a close to clinical practice and a patient-centered definition was established, defining it as excessive menstrual blood loss that interferes with the quality of life of a woman physically, socially, emotionally and/or materially which is accompanied whether or not by other symptoms⁴. This definition is based on studies in adult women with HMB where it was demonstrated that there is a physical, social and psychological impact and its treatment has been shown to improve their quality of life⁴⁻⁷.

In adolescence, main etiologies of HMB are anovulation due to immaturity of the hypothalamic-pituitary-gonadal axis and congenital or acquired coagulopathies in a variable percentage (10-62%), mainly von Willebrand's disease (3-36%) and platelet dysfunction (3-44%)⁸⁻¹⁰.

The prevalence of HMB in adolescents is not well defined, in part, because it can be considered normal within development, both for the family that does not visit or does it too late, and for the health care team that does not explore or dismiss this diagnosis until complications occur such as major bleeding, acute or chronic anemia secondary to excessive iron losses. In addition, adolescents may have difficulty in recognizing a pattern of normal menstrual bleeding³ and their references, which are the other women in the family, may have had or have HMB, especially in the context of familial coagulopathy, despite this, there are data in Brazil, Malaysia, Sweden, Nigeria and India that report prevalence rates between 1-37%¹¹⁻¹⁵.

There is no quality of life measurement tool for adolescents with HMB. However, there are instruments validated for adolescents regarding the perception of quality of life in health, such as the PedsQL 4.0 generic scale, which has been shown to differentiate between healthy adolescents and adolescents with comorbidities¹⁶. In Chile, it has language validation and it was previously used to measure quality of life in hemophilia patients¹⁷.

Since there is no local information on this subject, the aim of this study is to measure the impact on quality of life in Chilean adolescents with HMB.

Patients and Method

Subjects

Descriptive cross-sectional study that included adolescents between 10 and 18 years old with one of their guardian, who consulted in child and youth gynecology and/or hemostasis of the UC Christus health network, between October 2015 and January 2017. All the adolescents included were diagnosed with HMB by a gynecologist or an hematologist and those that besides HMB had decompensated chronic pathologies were excluded.

Instruments

Quality of life was measured with the PedsQL questionnaire version 4.0 generic scale, format 8-12 years or 13-18 years and the Proxy version PedsQL 4.0 for the guardian. The latter is a questionnaire identical to the adolescent one but based on the guardian perception of it. It was applied face-to-face at the doctor office or by telephone after the visit. The questionnaire intellectually belongs to James W. Varni, PhD¹⁶. PedsQL 4.0 consists of 23 questions and evaluates 4 dimensions of quality of life: physical, social, emotional and school, which are summarized in two categories: physical health (physical dimension) and psychosocial (average of social, emotional and school dimension). The responses were rated on the Likert scale. The score was transformed as follows: 0 = 100 points, 1 = 75 points, 2 = 50 points, 3 = 25 points, 4 = 0 points and averages were obtained. Higher scores mean better quality of life.

In addition, a survey was carried out of 3 HMB-related and everyday activities questions of the adolescents. Demographic, clinical and laboratory examination data were obtained from the electronic clinical record.

Statistical analysis

There are no Chilean studies of HMB prevalence, so the number of guardian-adolescent binomials recruited was for convenience. Statistical analysis was descriptive with average and standard deviation for continuous variables and proportions for categorical variables.

The concordance between the adolescent self-report and the proxy version of the guardian was determined with the Bland and Altman plot¹⁸, which was constructed with the difference between the total score of PedsQL 4.0 of the guardian minus the adolescent score (delta) and the average of the total score PedsQL 4.0 between both participants, in addition the average delta was calculated which corresponds to the average of the total difference in the total score of all the guardian-adolescent binomials. Concordance was consi-

dered acceptable if differences in average deltas ± 2 SD (normal distribution) are not clinically significant, in other words, they do not affect patient management decisions. The distribution of average deltas was determined with the Shapiro-Wilk test and considered a 95% confidence interval. Statistical analysis was performed using the SPSS statistical software version 22.

This study was approved by the scientific ethics committee of the Pontifical Catholic University of Chile, informed consent and assent for children under the age of 18.

Results

Demographic and clinical characteristics of adolescents

A total of 46 adolescents and one of their guardians were recruited during the study period. 52.2% of the questionnaires were answered in person. Table 1 shows the demographic and clinical characteristics.

A 34.8% ($n = 16$) of the total patients had alterations in coagulation tests, taking into account coagulation tests (PT, aPTT), study for von Willebrand's disease, platelet aggregation and euglobulin clot lysis time in platelet-rich plasma, recently added to evaluate fibrinolysis¹⁹. Von Willebrand's disease represents a 37.5% of our sample and the new study incorporated showed a 43.75% of alteration in fibrinolysis.

43.9% of the adolescents presented anemia at some point of their evolution, evidenced by hemoglobin lower than 12 g/dL or ferritin lower than 13 ng/mL. A 33.3% had anemia at the time of the study. One patient required red blood cell transfusion and 3 required inpatient care for acute anemia.

Quality of life measured with PedsQL 4.0

The questionnaire was administered to 46 adolescents and the proxy version to one father and 45 mothers of the adolescents. Table 2 shows the descriptive statistics of total score and dimensional scores for adolescent and guardian.

The average total score for adolescents was 64.48 (SD 14.54), with the emotional dimension having the lowest score, 55.33 (SD 18.27) and the social dimension having the highest score 82.5 (SD 13.69).

Concordance between adolescent and guardian

Among the guardians surveyed there was only one father who was excluded for concordance analysis considering that he might introduce some bias. Figure 1 shows the Bland and Altman plot for concordance.

The average delta for total score was -5.16 (SD 13.88) with a minimum value of -44.91 and a maximum of 27.17. The application of the Shapiro-Wilk

test for the average delta resulted in a $p = 0.513$ non-significant, which proves a normal distribution of the average delta, therefore, due to this distribution it can

Table 1. Demographic and clinical characteristics of adolescents

Characteristic	Measure
Average age. Years, months ($\pm$ SD years)	14.10 (2)
Age range, n (%)	
10-12 years	10 (21.7)
13-18 years	36 (78.3)
Average age of menarche. Years, months ($\pm$ SD years)	11.7 (1)
Dysmenorrhea, n (%) ^a	
Yes	18 (54.5)
No	15 (45.5)
Nutritional diagnosis, n (%) ^b	
Eutrophy	12 (44.4)
Overweight	11 (47.7)
Obesity	4 (14.8)
Coagulation study, n (%) ^c	
Coagulation disorder	16 (34.8)
Von Willebrand's disease	6 (13)
Hyperfibrinolysis	7 (15.2)
Platelet dysfunction	3 (6.5)
Hemophilia A Carrier	1 (2.2)
No study	17 (37)
Incomplete study	12 (26.1)
Diagnosis, n (%)	
HMB	24 (52.2)
Coagulation disorder	16 (34.8)
Supected coagulation disorder	5 (10.9)
Endometrial polyp	1 (2.2)
Transfusions, n (%)	1 (2.2)
Inpatients, n (%)	3 (6.5)
Anemia ever in life ^d	
Yes	18 (43.9)
No	23 (56.1)
Anemia at the time of PedsQL 4.0, n (%) ^e	
Yes	13 (33.3)
No	26 (66.7)
Maternal History of HMB, n (%) ^f	
Yes	15 (60)
No	10 (40)

SD: Standard deviation. ^a33 patients has the data for this measure. The percentage was calculated for a total n of 33. ^b27 patients has the data for this measure. ^cOne patient has two diagnosis. The percentage was calculated with her in the two groups. The percentage was calculated for a total n of 46. ^d41 patients has the data for this measure. ^e39 patients has the data for this measure. ^f25 patients has the data for this measure.

Table 2. Descriptive scale PedsQL versión 4.0: Adolescent and guardian

Scale	Average (SD)	Minimum	Maximum
Adolescent			
Total Score	64.48 (14.54)	18.48	88.04
Physical health	61.80 (19.18)	15.63	93.75
Psychosocial health	65.91 (14.45)	20.00	90.00
Emotional dimension	55.33 (18.27)	0.00	90.00
Social dimension	82.50 (13.69)	55.00	100.00
School dimension	59.89 (14.45)	5.00	100.00
Guardian			
Total Score	59.96 (17.73)	16.30	94.57
Physical health	58.72 (22.40)	9.38	100.00
Psychosocial health	60.60 (17.58)	20.00	93.33
Emotional dimension	46.52 (20.76)	0.00	85.00
Social dimension	77.02 (18.82)	35.00	100.00
School dimension	57.99 (23.22)	10.00	100.00

DS: Standard desviación.

Table 3. Activities limitations

Question	n (%)
Days of school absence during the menstrual period	
None	23 (50)
1 day	12 (26.1)
2 days	7 (15.2)
≥ 3 days	4 (8.7)
Absence of parties or outdoor activities	
Yes	30 (65.2)
No	16 (34.8)
Absence of physical education	
Yes	37 (80.4)
No	9 (19.6)

be said that 95% of the population of mothers with daughters with HMB in Chile would have their average deltas distributed among the average $\pm$ 2SD, that is to say, between -32.36 and 22.05 with a confidence interval of 95 % [-9.22, -1.10].

Activities limitations

Table 3 shows the activities limitations, highlighting that 80.4% of the adolescents have been absent from physical education and 65.2% have been absent from parties or outdoor activities. Additionally, in clinical records it was found reports of stained clothing and the need for frequent overnight clothes changes.

Discussion

Our study shows that the quality of life in adolescents with HMB measured with PedsQL 4.0 generic scale is affected, with the emotional dimension being the most compromised. We do not have a control group that allows us to compare with adolescents without HMB, but Varni et al. proposed that scores lower than 1 SD from the average imply a risk situation for deterioration in quality of life. The average population of healthy children between 5 and 16 years old was 83.91 (SD 12.47), so that averages under 71.44 are at risk of deterioration in quality of life¹⁶. In our study, 65.2% of the adolescents meet this condition. The total score of PedsQL 4.0 obtained by Varni et al. for chronic diseases is 74.16 (SD 15.38), being lower in our study. This lower score could be explained by the fact that in our study we only evaluated adolescents and it has found that life satisfaction may decrease during this period²⁰.

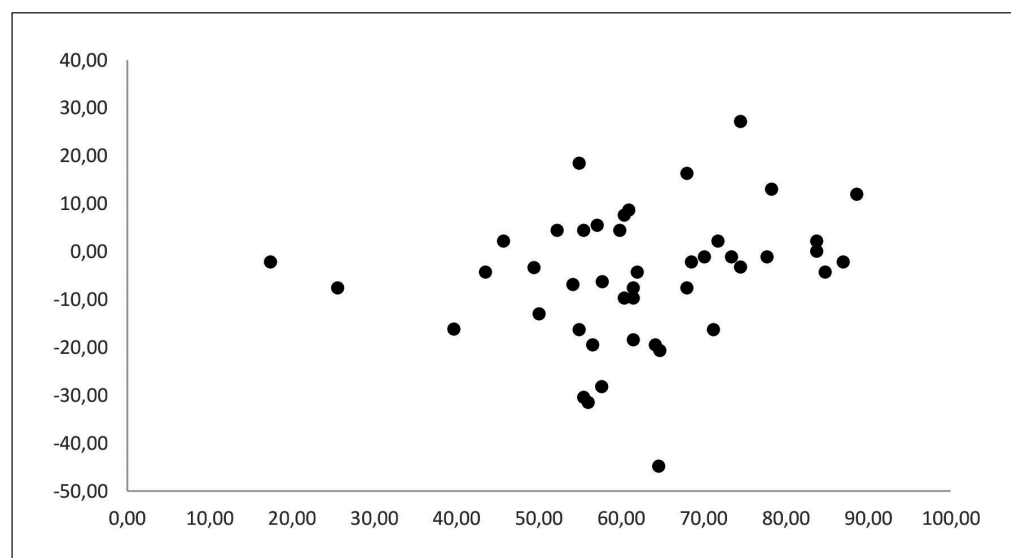


Figure 1. Bland and Altman Plot. Abscissa: Average of the total PedsQL score between the mother and daughter. Ordinate: difference of the total PedsQL score between the mother and the daughter.

In addition, there are limitations given by the sample size that can influence in this result: it was not adjusted for variables such as body image perception, amount of bleeding, degree of anemia, mood disorders. Finally, it should be considered that they are adolescents who consult at the secondary level which may represent the most severe cases.

In an Australian study of adolescents referred to gynecology for menstrual disorders, quality of life was measured with PedsQL 4.0 in 62 HMB patients. The total score was 71.23 (SD 15.19) and the dimension most affected was the school one²¹. The value obtained in our study was lower. This could evidence a cultural influence on the perception of quality of life.

Few adolescents seek help for menstrual problems¹⁵. Consequently, it is impressive that the adolescents who consult for HMB are those whose quality of life is already very affected, due to the fact that HMB has been prolonged over time, producing symptoms of iron deficiency anemia and psychosocial alterations. On the other hand, the perception of the mother of HMB as a problem, often determines the access of the adolescent to the health system. Our study found that mothers rate their daughters, on average, with 5.16 points less than what their daughters perceive, which impresses irrelevant, however, individual values can vary by 32.36 points less than what their daughter reports as 22.05 points more, therefore, the degree of agreement between binomials individually is not acceptable. This emphasizes the importance of direct and separate interviews with the adolescent and her mother about how they perceive quality of life. This phenomenon could be explained because the perception of the mood of the adolescent by her guardian is subjective, so communication is important. There may be a barrier to communication on the part of the adolescent if she considers the HMB as something embarrassing and this explains why some mothers attribute higher scores to their daughters than they do. On the other side, as it has been seen in other chronic diseases such as inflammatory bowel disease, symptoms can be minimized by adolescents as an adaptive reaction in order to deny the extent of the disease^{22,23} and for this reason mothers perceive a lower quality of life than adolescents themselves. Furthermore, there are other not explored factors in this study that could affect the perception of quality of life, either undervaluing or overestimating it, such as maternal mood, family situation, one's own experience of menstruation and maternal education.

During excessive menstruation, anxiety for frequent stain often leads to have to choose appropriate clothing, to have to put on mattress protectors, frequent changes at night, which can lead to social and

personal limitations during menstruation²⁴. In our study, 50% of the adolescents skip school and in the most severe cases they could lose one month a year of classes. Since menstrual hygiene is complicated by limited time between classes, it would be interesting, in the future, to determine if this limitation is a factor influencing school attendance in order to generate interventions.

Finally, although the objective of this work is not to diagnose pathology, it should be noted that what is described in the literature is confirmed with 34.8% of altered tests suggestive of coagulopathy, which reinforces the need for study and multidisciplinary approach.

In conclusion, the study shows that quality of life is affected in adolescents with HMB who consult health professionals, resulting in school truancy, limited social activities, anemia, hospitalizations and/or the need for red blood cell transfusion. The early detection and study of an HMB, including a complete hematological study in pursuit of clotting disorders, is essential to avoid associated complications. It remains to be demonstrated if early detection and treatment of HMB improves the quality of life in adolescent as evidenced in adults.

Ethical Responsibilities

Human Beings and animals protection: Disclosure the authors state that the procedures were followed according to the Declaration of Helsinki and the World Medical Association regarding human experimentation developed for the medical community.

Data confidentiality: The authors state that they have followed the protocols of their Center and Local regulations on the publication of patient data.

Rights to privacy and informed consent: The authors have obtained the informed consent of the patients and/or subjects referred to in the article. This document is in the possession of the correspondence author.

Financial Disclosure

Authors state that no economic support has been associated with the present study.

Conflicts of Interest

Authors declare no conflict of interest regarding the present study.

References

1. Peacock A, Alvi NS, Mushtaq T. Period problems: disorders of menstruation in Adolescents, *Arch Dis Child*. 2012;97:554-60.
2. Munro M, Critchley H, Broder M, Fraser I. FIGO classification system (PALM-COEIN) for causes of abnormal uterine bleeding in nongravid women of Reproductive age. *International Journal of Gynecology and Obstetrics*. 2011;113:3-13.
3. ACOG Committee Opinion No. 651: Menstruation in Girls and Adolescents: Using the Menstrual Cycle as a Vital Sign. *Obstet Gynecol*. 2015;126: e143-6.
4. NICE clinical guideline 44, Heavy menstrual bleeding, 2007.
5. Hurskainen R, Aalto AM, Teperi J, et al. Psychosocial and other characteristics of women complaining of menorrhagia, with and without actual increased menstrual blood loss. *BJOG: an international journal of obstetrics and gynaecology* 2001;108:281-5.
6. Coulter A, Peto V, Jenkinson C. Quality of life and patient satisfaction following treatment for menorrhagia. *Family Practice*. 1994;11:394-401.
7. Spies JB, Warren EH, Mathias SD, et al. Uterine fibroid embolization: measurement of health-related quality of life before and after therapy. *Journal of Vascular and Interventional Radiology*. 1999;10:1293-303.
8. Jayasinghe Y, Moore P, Donath S, Campbell J, Monagle P, Grover S.: Bleeding disorders in teenagers presenting with menorrhagia. *Aust N Z J Obstet Gynaecol*. 2005; 45:439-43.
9. Vo KT, Grooms L, Klima J, Holland-Hall C, O'Brien SH. Menstrual bleeding patterns and prevalence of bleeding disorders in a multidisciplinary adolescent haematology clinic. *Haemophilia*. 2013;19:71-5.
10. Seravalli V, Linari S, Peruzzi E, Dei M, Paladino E, Bruni V. Prevalence of hemostatic disorders in adolescents with abnormal uterine bleeding. *J Pediatr Adolesc Gynecol*. 2013;26:285-9.
11. Wilkinson J, Kadir R. Management of abnormal uterine bleeding in adolescents. *J Pediatr Adolesc Gynecol*. 2010;23:S22-S30.
12. Harlow SD, Campbell OM. Epidemiology of menstrual disorders in developing countries: a systematic review. *BJOG*. 2004;111:6-16.
13. Pitangui A, Gomes M, Lima A, Schwingel P, Albuquerque A, Cappato de Ara R. Menstruation Disturbances: Prevalence, Characteristics, and Effects on the Activities of Daily Living among Adolescent Girls from Brazil. *J Pediatr Adolesc Gynecol*. 2013;26:148-52.
14. Friberg B, Ornö AK, Lindgren A, Lethagen S. Bleeding disorders among young women: a population-based prevalence study. *Acta Obstet Gynecol Scand*. 2006;85(2):200-6.
15. Lee LK, Chen P, Lee KK, Kaur J. Menstruation among adolescent girls in Malaysia: a cross-sectional school survey. *Singapore Med J* 2006;4:869-74.
16. Varni J, Burwinkle T, Seid M, Skarr D. The PedsQL 4.0 as a Pediatric Population Health Measure: Feasibility, Reliability, and Validity. *Ambulatory Pediatrics*. 2003;3:329-41.
17. Plaza M, Calidad de vida de los niños hemofílicos de 8 a 12 años de la región metropolitana de Santiago de Chile 2005 Tesis, Universidad de Chile facultad de medicina escuela de salud pública.
18. Bland J, Altman D, Statistical methods for assessing agreement between two methods of clinical measurement, *Lancet*, 1986; i: 307-310.
19. Panes O, Padilla O, Matus V, Sáez CG, Berkovits A, Pereira J, et al. Clot lysis time in platelet-rich plasma: Method assessment, comparison with assays in platelet-free and platelet-poor plasmas, and response to tranexamic acid. *Platelets* 2012; 23(1):36-44.
20. Goldbeck L, Schmitz T, Besier T, Herschbach P, Henrich G. life satisfaction decreases during adolescence. *Qual Life Res* 2007; 16: 969-79.
21. Nur Azurah A, Sanci L, Moore E, Grover S. The quality of life of adolescents with menstrual problems. *J Pediatr Adolesc Gynecol* 2013;26:102-8.
22. Cunningham C, Drotar D, Palermo TM, McGowan K, Arendt R. Health related quality of life in children and adolescents with inflammatory bowel disease. *Child Healthcare* 2007;36:29-43.
23. Mackner LM, Crandall WV, Szigethy EM. Psychosocial functioning in pediatric inflammatory bowel disease. *Inflamm Bowel Dis* 2006;12:239-44.
24. Sociedad española de ginecología y obstetricia. Sangrado menstrual abundante (SMA). *Prog Obstet Ginecol* 2013;56:535-6.