

# HAEMO-QOL QUESTIONNAIRE FOR ADOLESCENTS: ASSESSING THE ITEM BLEEDING

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## OBJECTIVES

How hemophilia is a hereditary type of coagulopathy, manifested by the occurrence of bleeding events, and the main clinical manifestation is reflected in joint bleedings, it may be a reason of changes in quality of life, especially in adolescents.

The objective of this study is to evaluate the "bleeding item" Quality of Life Questionnaire of the Haemo-QoL for adolescents with hemophilia.

## METHODS

This work is part of a doctorate study, about the quality of life of hemophilic persons who live in Curitiba and metropolitan area, Brazil. It is a descriptive, cross-sectional quantitative approach. It was used the Haemo-QoL questionnaire for adolescents (13-16 years), validated in Brazilian Portuguese, in persons with haemophilia A and B, that was contacted by phone and they came to hemocentre to be examined, and answer the questionnaire.

It was excluded those who haven't been found or those whose parents didn't agree to participate in the study, not signing the consent form.

It was analysed the first question: "Bleedings", where it is analysed 5 sub-items, how is shown in the graphic below. It was made the summary of sub-items, the maximum score is worst quality in this item; the minimum admitted is 6 and maximum 16.

Here we would like to know something about your **BLEEDS (JOINT BLEEDS)**.

1. How frequent were your bleeds in the last 4 weeks?  
 no bleeds  1  2  more than 2    How many? \_\_\_\_

The following questions should only be answered if you had bleeds.


2. How much were you troubled by bleeds during the last 4 weeks?  
 not at all  somewhat  moderately  quite a bit

3. How severe were your bleeds during the last 4 weeks (if you had several bleeds, please answer for the severest bleed)?  
 slight  moderate  severe  very severe

4. Did you feel a strange sensation in your joints before you had a bleed?  
 never  seldom  sometimes  often  always

5. Did you have to stay quiet (e.g. lie in bed) when you had bleeds?  
 never  seldom  sometimes  often  always

6. When you had bleeds, did you inform your parents immediately?  
 never  seldom  sometimes  often  always



## RESULTS

There were 18 adolescents with haemophilia, 12 of them answered the questionnaire, all of them have haemophilia A and 9 are severe. The minimum score found was 9 (one person with mild level of haemophilia) and maximum was 16 (two persons with severe level).

The data collection showed that 42% of patients had at least one episode of bleeding in the last month, 58% felt somewhat uncomfortable with the bleeding, 66% characterized as mild, 83% reported made sometimes a rest during the bleeding and 50% sometimes related for their parents about the hemorrhagic episodes.

## CONCLUSIONS

For patients with hemophilia, bleeding's monitoring, contributes to improve the quality of physical health, with a premature treatment, because in our country is beginning the primary prophylaxis. Specially for teens, who are in transition and are experiencing the diversity that life offers, is a way to prevent future complications. But the results show that boys don't have a good perception about this, maybe for a mechanism of "adaptation", because the diary contact with the pain makes them not recognize the bleeding severity, and one consequence is not to relate that episode to their parents. The literature confirms that the increase in bleedings can result in a decrease of quality of life, but it isn't unanimous. So, it's important the presence of a multidisciplinary team that involves the patient in an educational environment.

## REFERENCES:

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