

Well Being 378

introduction

This survey asks questions about a disorder known as Hemophilia, which is a bleeding disorder. We will begin by giving some background on the disorder and then have you choose some hypothetical treatment options. Click Next to begin.

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Background: Hemophilia is a genetic disorder that mostly affects men. It is caused by a deficiency of a substance (clotting factor) needed for the clotting of blood. Severe hemophilia implies that the patient has bleeding episodes, often in the joints, which can occur without apparent reason. The bleeding episodes are painful and will gradually lead to destruction of the joints and to disability. If the bleeding episodes are severe, or if they occur in the brain, the patient may die. Click Next to continue.

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Treatment options for hemophilia: Hemophilia can be treated in two ways: A) On-demand treatment (as needed only) and B) Prophylactic (Preventive) treatment. On-demand (As needed only) treatment: It implies that patient receives the drug when bleeding occurs to stop bleeding. Currently, patient/parent or caregiver needs to mix the drug to prepare solution for infusion. Sometimes, depending on the severity of the bleeding episode, patient may require dose-adjustment that could mean increase or decrease in drug (i.e. clotting factor) dose. Sometimes the patient may experience an undesirable effect (side effect) such as rashes. The purpose of on-demand treatment is to stop the bleeding as soon as possible. Click Next to continue.

introduction3b

Prophylactic (Preventive) treatment: It implies that the patient is given preventive treatment to prevent the bleeds from occurring altogether. The patient receives extra drug (i.e. clotting factor) through regular infusions, one to three times weekly. Currently, patient/parent or caregiver needs to mix the drug to prepare solution for infusion. Sometimes, depending on the severity of the bleeding episode, hemophilia patient may require dose-adjustment that could mean increase or decrease in drug (i.e. clotting factor) dose. Sometimes the patient may experience an undesirable effect (side effect) such as rashes. The purpose of prophylactic treatment is to prevent bleeding from occurring. Thereby the risk of pain and joint destruction because of bleeding could be reduced even further. Click Next to continue.

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Effectiveness of treatment options for hemophilia: Effectiveness of treatment relates to how well a given medical drug or treatment works on the patient. Both treatment strategies reduce the risk of joint destruction and disability. There are however other differences in the two treatment options: Several clinical studies have shown that prophylactic treatment may almost prevent bleeding entirely. Patients on prophylactic treatment have smaller risk of disability, fewer sick days and do not have to refrain from physical activity to the same extent as patients on on-demand treatment. However, due to frequent infusions prophylactic treatment takes considerable time and effort and is also far more expensive compared to on demand treatment.

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In the next few screens we will ask you to choose each time between two treatments. For each treatment we will provide you with information on its characteristics. Please read these carefully before making your choice.

LOOP FROM 1 TO 6 DO

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| IF New question = 1 THEN

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| ELSEIF New question = 2 THEN

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| ELSEIF New question = 3 THEN  
||  
| ELSEIF New question = 4 THEN  
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| ELSEIF New question = 5 THEN  
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| ELSEIF New question = 6 THEN  
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| ENDIF
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| **scenario** treatment choice

| If these were the only treatment options available, which one would you choose for a patient?

| Please note: if you wish to learn more about a treatment characteristic, just click on any of the
| links.

|
ENDDO

CS_001 HOW PLEASANT INTERVIEW

Could you tell us how interesting or uninteresting you found the questions in this interview?

1 Very interesting

2 Interesting

3 Neither interesting nor uninteresting

4 Uninteresting

5 Very uninteresting