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Hemophilia

Patient name: _____ Admission: _____

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I. The client/caregiver can define hemophilia.

- A. It is a hereditary bleeding disorder caused by a deficiency that is necessary for coagulation of blood.
- B. It can be a very mild to a very severe disorder:
 1. Clotting factors are between 5% and 25% in mild hemophilia.
 2. Clotting factors are between 1% and 5% in moderate hemophilia.
 3. Clotting factors are less than 1% in severe hemophilia.
- C. Hemophilia can be classified as A or B.
 1. Hemophilia A is a deficiency of factor VIII.
 2. Hemophilia B is a deficiency of factor IX.
- D. It is a recessive disorder transmitted by females and found predominantly in males.

II. The client/caregiver can recognize signs and/or symptoms of bleeding.

- A. Hemophilia is suspected in newborns if there is excessive bleeding from the umbilical cord or after circumcision.
- B. Major signs and symptoms are
 - Bleeding
 - Bruising
- C. The extent of bleeding depends on the type and severity of the hemophilia.
- D. In most children with hemophilia, the first signs/symptoms are
 - Heavy bruising and bleeding from gums when they cut baby teeth
 - Bumps and bruises that appear frequently when they learn to walk
 - Joints that have swelling and bruising from bleeding in soft tissue and muscles
- E. In older children, the signs/symptoms are
 - Bleeding in the joints (hemarthrosis)
 - Bleeding and bruising in soft tissue and muscles
 - Bleeding in the mouth from cut or bite or loss of a tooth
 - Nosebleeds for no reason

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- Blood in the urine (bleeding in kidneys or bladder)
- Blood in the stool (bleeding in intestines or stomach)
- F. Children with severe hemophilia have bleeding in the joints as the most common problem.
 1. The most common joints to have bleeding are the knees, elbows, and ankles.
 2. The signs/symptoms of bleeding in the joints are
 - Tightness in the joint without real pain
 - Tightness and pain that may occur before visible signs of bleeding
 - Joint that becomes swollen and hot to touch; pain that is experienced with any movement
 - Swelling and severe pain that can result in a loss of movement
 3. If not treated, bleeding can lead to permanent damage and arthritis.
- G. Bleeding in the brain is a serious complication and requires emergency treatment. The bleeding can happen after only a small bump or injury to the head.
 1. Signs and symptoms of bleeding in the brain are
 - Long-lasting and painful headache
 - Multiple episodes of vomiting
 - Changes in behavior
 - Becoming very sleepy
 - Sudden weakness or clumsiness of arms or legs, including difficulty walking
 - Double vision
 - Convulsions or seizures

III. The client/caregiver can list ongoing medical needs for the person with hemophilia.

- A. Ask for referral to any of the Hemophilia Treatment Centers in the U.S. (Directory of Hemophilia Treatment Centers—www.cdc.gov/ncbddd/hbd/htc_list.htm).

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- They can help your local care provider to meet your special needs.
- B. Continue treatments as prescribed.
- C. Have regular checkups and immunizations as recommended.
- D. Have regular dental care.
- E. Learn the signs and symptoms of bleeding in the joints.
- F. Contact your health care provider or go to the emergency room if these symptoms appear:
 - Heavy bleeding that cannot be stopped or continues to ooze
 - Any of the symptoms of bleeding in the brain
- G. Try to keep a record of all treatments with you to appointments or emergency room visits.

IV. The client/caregiver can list necessary precautions for the young child with hemophilia.

- A. Use kneepads, elbow pads, and protective helmets. Use car seat belts properly.
- B. Use the safety belts and straps in highchairs, car seats, shopping carts, and strollers.
- C. Remove furniture with sharp corners or pad them carefully.
- D. Keep any small and sharp objects out of the reach of child.
- E. Use cabinet safety locks, electrical outlet covers, and security gates to keep child away from stairs.
- F. Monitor play equipment and outdoor public play areas for possible hazards.
- G. Keep cold packs in the freezer to use quickly.
- H. Prepare a bag with needed supplies and information if you need to take child to emergency room.
- I. Notify anyone who is responsible for your child of his or her condition. That may include the following:
 - Babysitters
 - Daycare providers
 - Teachers
 - Coaches
- J. Have child wear a medical alert bracelet.

V. The client/caregiver can list preventive measures for the adolescent with hemophilia.

- A. Teenager should learn signs of bleeding and what are the appropriate actions.

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- B. Exercise regularly and safely.
- C. Learn not to take unnecessary risks.
- D. Take care of teeth and gums.
- E. Recognize and eat a healthy diet.
- F. Possibly participate in administration of medications needed.
- G. Some examples of safer physical activities are as follows:
 - Swimming
 - Biking (wearing appropriate equipment)
 - Walking
 - Golf
- H. The contact sports such as football, hockey, or wrestling are not usually considered safe.
- I. Wear Medical Alert bracelet.

VI. The client/caregiver can list measures to help with emotional factor of hemophilia.

- A. Educate about disease and treatment in a way that he or she can understand.
- B. Reassure that the disease is not the fault of child.
- C. Encourage child to participate in their own care (as age of child is appropriate).
- D. Offer support group participation for both client and family.

VII. The client/caregiver can list possible complications.

- A. Joint deformities
- B. Life-threatening bleeding

RESOURCES

National Hemophilia Foundation
www.hemophilia.org

National Heart, Lung, and Blood Institute
www.nhlbi.nih.gov

Support groups

REFERENCES

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