

HAEMOPHILIA HEREDITARY, BLOOD DOESN'T CLOT

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"The recommended approach is to use a preventative strategy by administering treatment regularly, for example, two-three times a week. This calls for factor availability in large amounts, which is not very feasible in poorer countries," he said. He said the dose for the injection depends on the patient's weight. "For example, for a 20kg child, it would cost about \$500 (approximately sh1.85m) and an adult of 60kg would pay \$1,500 per shot (approximately sh5.56m)," he said.

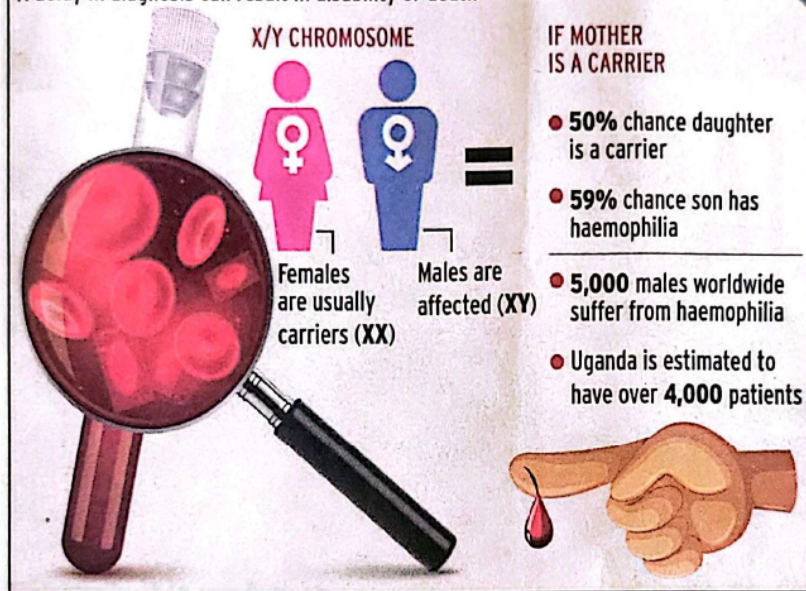
Dr Wasswa said the factor concentrate in Uganda comes as a donation from the World Federation of Haemophilia to the Uganda Haemophilia Foundation (UHF), which helps the poor access it.

"From UHF, it is distributed to haemophilia treatment centres found at Mulago and other hospitals. It is free for patients. However, stock outs happen when drug shipments are delayed. A process is ongoing to interest the government to purchase factor, but obviously there are also very many pressing needs for government," he explained.

On the other hand, Dr Wasswa said sometimes patients can be treated with a less effective option called fresh frozen plasma or cryoprecipitate (these are processed from blood donations), when factor concentrate is out of stock.

How haemophilia is inherited

Haemophilia is a hereditary disease where blood does not clot as it should. A delay in diagnosis can result in disability or death



NUTRITION

A person suffering haemophilia does not have special dietary regimen. Dr Wasswa said they encouraged to have a normal balanced diet. "There are no dietary restrictions," he said.

SUPPORT GROUP

Being a part of support groups is important for haemophilia and other chronic conditions, Dr Wasswa noted. "They provide a platform for peer

support, advocacy, joint learning, psychosocial support among many other benefits. In Uganda, the Haemophilia Foundation of Uganda is one such organisation. It is a patient-led organisation," he said. The foundation supports patients and their families with treatment, as well as psychosocial support, such as counselling, explained Agnes Kisakye, the executive director of Haemophilia Foundation of Uganda. "We treat them

in partnership with Ministry of Health through regional hospitals. We also support families with counselling because they face stigma from families and society," she said. Since haemophilia is a rare disease, Kisakye said the foundation also supports health workers with capacity building so they can ably support patients.

Unfortunately, the foundation, Kisakye says cannot afford to test

FIRST AID

Since accidents can easily happen to anyone, it is even more important that a haemophilia sufferer receives the right first aid to stop the bleeding. Dr Wasswa shared the following as first aid for bleeding haemophilia patients:

1. Stop the bleeding inducing activity, if that's possible e.g stop any active trauma
 2. Arrest the bleeding where feasible, for example, by applying pressure to an externally bleeding cut.
 3. Check patient has stable signs of life (breathing pattern and regular heart rate)
 4. The patient should be taken to hospital where the deficient factor is administered immediately, for example, factor VIII or factor IX concentrates or using fresh frozen plasma.
 5. Treat pain
- Dr Kasirye added that: "First Aid involves applying pressure at the point of injury, reduced movements and application of ice-cold measures. Ice cold measures are RICE (Rest, Ice, Compression, Elevation) protocol used to manage joint and muscle bleeds.

carriers because of financial constraints. "If we could test carriers that would be better, but we are constrained,"

Kisakye said.

The foundation also supports patients with life skills so that they can support themselves.

"We support patients get skills like entrepreneurship because the disease makes miss classes and they drop out of school for treatment and some do not complete school, so they need skills to earn a living."

LATEST RESEARCH

Currently, research is focused on producing more effective treatments to allow patients live a normal and unrestricted lifestyle. "Advances include gene therapy, by correcting the genetic defects in the cells that produce factor. This is expensive and can cost millions of dollars," Dr Wasswa said.

Other efforts, he added, are geared to produce treatments that last longer in the body, resulting in less frequent injections. "Others products also mimic the work of clotting factors to bypass the need for the deficiency factors. Other products are made to increase the effect of the clotting activity," Dr Wasswa said.

ADVICE

Dr Wasswa advised mothers with affected sons or daughters with affected brothers or maternal uncles to have their male offspring tested. "And if pregnant with a boy to undertake measures that reduce the risk of bleeding, such as reducing invasive foetal monitoring," he said.