SUARA KONTEMPORARI
Kosmo!

‘Setiap dua minggu sekali saya masuk wad’

- Oleh MUHAMMAD FARID AHMAD TARMIJI
- 6 September 2024, 8:34 am

MASALAH hemofilia yang dihadapi oleh Hariee Prabakaran telah menyebabkan dia tidak dapat menjalani kehidupan dengan lebih sejahtera sebagaimana orang lain. Hemofilia adalah satu keadaan yang berpunca daripada kekurangan faktor pembekuan darah.

Disebabkan masalah itu, dia kerap mengalami pendarahan pada sendi seperti lutut dan siku.

“Masalah ini telah mengehadkan pergerakan sendi dan membuatkan saya kerap masuk wad untuk mendapatkan rawatan.

“Hampir dua minggu sekali saya akan masuk wad. Sebab itu saya tidak dapat hadir ke sekolah ketika di alam persekolahan,” katanya yang kini berusia 22 tahun.

Tambahnya, disebabkan masalah itu, dia juga mengalami kesukaran untuk mendapatkan kawan pada zaman persekolahan.

Katanya, kebanyakan rakan sekelasnya ragu-ragu untuk bercakap dengannya apabila mereka mengetahui dia mempunyai penyakit hemofilia.

Namun kini, selepas melalui rawatan ubat yang diberikan, dia jarang mengalami pendarahan pada sendi.
Ubat itu boleh mencegah penda

Dalam pada itu, mengulas tentang masalah hemofilia, Perunding Pediatrik Hematologi dan Onkologi Hospital Tunku Azizah Kuala Lumpur, Dr. Zulaiha Muda berkata, hemofilia adalah salah satu penyakit kategori jarang jumpa.

Menurutnya, masalah itu adalah keadaan di mana badan kekurangan faktor pembekuan darah dan tidak berupaya untuk membeku darah yang merupakan proses penting untuk memberhentikan pendarahan.

“Ini menyebabkan pesakit hemofilia boleh berdarah dalam masa lama jika berlaku trauma, mudah lebam dan risiko pendarahan dalam sendi serta organ.

“Penyakit ini adalah penyakit genetik apabila mutasi genetik diturunkan daripada ibu yang merupakan pembawa hemofilia gen (70 peratus kes) atau mutasi genetik spontan berlaku pada pesakit itu sendiri (30 peratus kes),” katanya.

Jelas Dr. Zulaiha, terdapat dua jenis hemofilia yang utama iaitu hemofilia A disebabkan kekurangan faktor VIII dan hemofilia B akibat kekurangan faktor IX.

Dalam pada itu, simptom utama penghidap hemofilia adalah masalah perdarahan.

Keterukan dan kekerapan perdarahan penghidap hemofilia bergantung kepada paras faktor pembekuan darah pada badan penghidap.

Hemofilia boleh dikesan melalui ujian darah. – Gambar hiasan
Dr. Zulaiha menjelaskan, paras normal bagi faktor pembekuan adalah 40 peratus sehingga 150 peratus, namun bagi pengidap hemofilia adalah kurang 40 peratus.

“Semakin rendah tahap faktor pembekuan, semakin tinggi risiko untuk berlaku simptom perdarahan.

“Tahap keterukan hemofilia terbahagi kepada tiga iaitu hemofilia ringan (mild haemophilia), hemofilia sederhana (moderate haemophilia) dan hemofilia serius (severe haemophilia),” katanya.

Simptom-simptom pendarahan boleh berlaku pada mana-mana bahagian badan.

Kadangkala ia boleh dilihat dan ada masanya ia tersembunyi.

Penghidap hemofilia serius akan mengalami pendarahan yang lebih teruk dan kerap, sementara hemofilia ringan selalunya mengalami simptom ringan kecuali jika berlaku kecederaan serius atau selepas melakukan pembedahan.

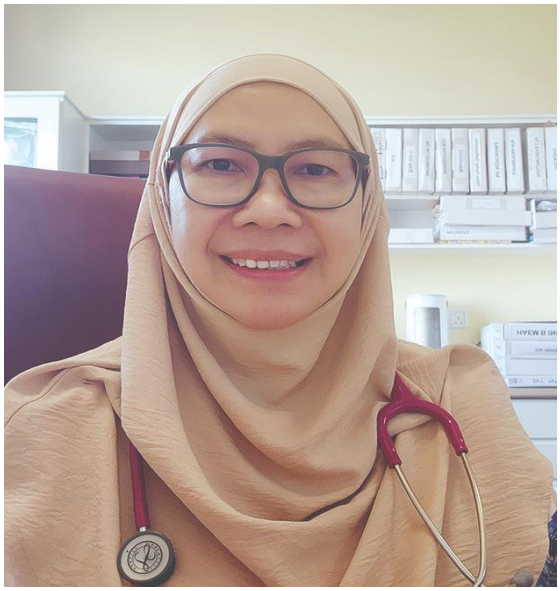
Bagi kes hemofilia sederhana, simptomnya adalah dalam spektrum antara yang serius dan ringan.

Menerangkan tentang simptom hemofilia, Dr. Zulaiha berkata, pesakit mudah lebam secara spontan atau akibat kecederaan yang sangat minimal terutama kepada bayi yang belajar merangkak atau berjalan.

“Lebam atau hematoma yang serius boleh juga berlaku selepas suntikan vaksin.

“Pendarahan yang berlebihan dan tidak munasabah (unexplained) akibat luka atau trauma, selepas cabut gigi atau pembedahan seperti bersunat.

“Pendarahan ini juga mengambil masa lebih lama daripada biasa untuk berhenti,” ujarnya.



DR. ZULAIHA

Tambahnya, simptom lain termasuklah pendarahan dalam sendi yang menyebabkan sendi sakit, bengkak dan menyukarkan pergerakan. Ini boleh berlaku secara spontan atau akibat kecederaan yang ringan.

Jika tidak didiagnosis atau dirawat, penghidap hemofilia boleh mendapat komplikasi akibat pendarahan bergantung kepada bahagian badan terlibat dengan perdarahan.

Contohnya, pendarahan yang berulang dalam sendi terutama lutut dan siku menyebabkan kerosakan sendi dan cacat anggota badan.

Pendarahan otak menyebabkan pengsan, sawan dan maut. Pendarahan dalaman seperti dalam otot boleh menyebabkan bengkak, sakit dan masalah pergerakan.

Pendarahan di bahagian leher boleh menyebabkan bengkak dan mengganggu pernafasan.

Dr. Zulaiha berkata, diagnosis hemofilia dibuat melalui ujian darah iaitu ujian screening pembekuan darah (coagulation test).

Ujian ini bagi memastikan tahap faktor pembekuan dalam badan (factor assay) dan ujian genetik untuk menentukan jenis mutasi hemofilia.

“Manakala untuk rawatan hemofilia adalah melalui terapi penggantian faktor. Untuk penghidap hemofilia serius, faktor pembekuan akan diberi secara berkala antara sekali seminggu hingga tiga kali seminggu.

“Pemberian faktor pembekuan adalah melalui infusi ke dalam salur darah,” katanya.

Tambahnya, rawatan itu dipanggil profilaksis, di mana ia dapat mencegah pendarahan daripada berlaku terutamanya secara spontan.

Selain terapi prophylaxis, jika berlaku pendarahan, rawatan penggantian faktor akan diberikan secara intensif untuk memberhenti perdarahan.

Selain itu, terapi penggantian bukan faktor juga boleh dilakukan. Buat masa ini, terapi bukan faktor yang diluluskan adalah untuk hemofilia A.

Pemberian penggantian bukan faktor adalah secara suntikan di bawah kulit yang boleh diberi sekali seminggu, setiap dua minggu atau sebulan sekali.

Terapi bukan faktor ini sangat berkesan dalam mencegah perdarahan.

Selain itu, rawatan terapi gene juga boleh diberikan. Hemofilia boleh dipulihkan melalui terapi gene.

Terapi ini masih baru dan banyak kajian klinikal sedang dilakukan untuk mendapatkan terapi gene yang lebih efektif.

The Star

Make it safe for victims to seek help

By **FAZLEENA AZIZ**

- **NATION**
- Thursday, 19 Sep 2024

KUALA LUMPUR: Hospital Tunku Azizah Kuala Lumpur's Suspected Child Abuse and Neglect Team (SCAN Team) handles about 70 cases of child abuse monthly.

These cases are usually referred to it from the emergency department or from clinics.

The hospital's consultant paediatrician and adolescent specialist Datin Dr Sheila Marimuthum said when dealing with such cases, doctors often need to grapple with various forms of abuse.

These include physical, sexual, psychological and emotional abuse as well as omission of care like neglect, child labour, begging, not being sent to school, poor parental supervision, malnourishment and the list goes on.

As for the Welfare Department (JKM), most child abuse cases it receives are referrals from government hospitals.

With cases of child abuse raising much concern, Dr Sheila, who has over 30 years' experience as a paediatrician, speaks to The Star on the battle against the scourge and the complex issues involved.

What are some of the signs of a child being a victim of abuse, physically or sexually?

I would say that the hallmark of child abuse diagnosis is undertaking a thorough history. A paediatrician or emergency doctor should elicit a very good history. From there, our index of suspicion will be higher and we can proceed with the examination.

In terms of signs, first of all, we look at why the child came to the hospital and at the symptoms such as pain, a broken bone, bruises, lacerations, abrasions, seizures, vaginal pain, discharges or bleeding and others that raise concerns.

We also look into the history of the family or carers of these patients and rule out actual accidents or traumas. From that point, we slowly get into gathering a very good social history and zoom in. The examination will predominantly be directed by the presenting complaints.

For example, if a child is a suspected victim of sexual abuse, there might be direct history from the mother or indirect history of behavioural changes, which warrants further questioning or there might be some discharge or pain, or sometimes bleeding in the genital area. This involves a multi- disciplinary approach with emergency doctors, paediatricians and gynaecologists coming together.

For children, we have an SOP for handling cases and we document the exact nature of the injuries in terms of the size, site and approximate timing of injuries. We also do laboratory investigations, produce medical reports for the police and judiciary later on and even appear in courts.

What happens following the discovery by the doctor?
If we suspect that the case occurred outside the home, it is easier to bring the parents on board. We would explain to them based on the signs and symptoms, so cooperation is better. We then proceed as per protocol.

But if we suspect the abuse to be intrafamilial or we suspect someone in the home, this is where it gets tricky. We will explain about the need for admission and further investigation, and it does get sensitive involving family members most times.

We have to be tactful, but the protection and safety of the child is also most important.

What happens when the perpetrators are family members or male relatives?
There are cases where the mothers may not want us to make a police report or proceed with the case. But we are fortunate to have good laws in the country like the Child Act (2001), which protects the rights of children.

The aim is always to act in the best interest of the child so if we have room for suspicion, then the doctor can activate the child protection officer (Pasukan Pelindung) and the police. We will try to convince the parents of the need to investigate, and protect the child.

What are the causes of this happening in families?
There are multiple possible causes. Among them are a coping mechanism, which is probably poor in the family, a social economic history with triggering factors like financial problems, substance or alcohol abuse, and mental health disorders. There is definitely an increased chance of children being abused in spousal/domestic violence.

What are some of the challenges a medical personnel faces in such a situation?
Some challenges include being threatened and possibly attacked, but we have the law on our side to proceed with such cases.

If they do not want to cooperate and refuse admission, the child protection officer and police will assist. In most cases, we are successful in getting them admitted for further examination or interviews.

Why is it more difficult for boys who are victims of sexual abuse to open up?
Studies have shown that girls are more open and expressive, compared to boys who think it is not macho to talk about their feelings. But honestly, we cannot ascertain for sure why they hold back; whether it is because they feel ashamed to come forward or because there is a cultural norm at work here.

What should we change within society, especially the family unit, to break the cycle of abuse?
First of all, we have to address the issue of domestic violence by empowering women or those who are being abused. Within the community, we need people out there to help educate victims about where to find help. The victim should be able to walk into a community centre or approach village leaders or a teacher for help.We need mechanisms in place to help these victims. Even though there are NGOs, many of these women still don't know where to go. Also, mothers might be worried about the financial burden if their breadwinners are turned in. There needs to be a mechanism to help these families financially at the point of reporting.

We have also seen many teachers picking up cases of child abuse, especially among children with behavioural changes. I think it is excellent that teachers and school counsellors have been trained to pick out these children. But there are some children who are worried about confidentiality and might not seek help. We need to empower young victims to seek help and educate them.

I have been in this field for almost 32 years and have seen improvements at the professional level with doctors able to identify cases with confidence.

The referral system has improved and cooperation from the police (D11) as well as our greatest ally, JKM, has been excellent. We also have SCAN Team meetings in most hospitals, which has improved networking among the agencies.

Do you think there should be changes in terms of who is mandated to report abuse that can help mainly people dealing with children?
Neighbours, teachers and anyone in the community could be roped in to report such cases. Most of the time, people make anonymous calls because it is safer, especially if you live within a community as you don't want trouble. Talian Kasih (15999 or Whatsapp 019-261 5999) are still some of the best ways to make a report.

What are other elements you think should be included to tackle threats online?
Parents need to have some control or better control of their children and screen time. I have seen many parents let go of supervision. This is important because you cannot let your children be online for hours without any sort of supervision.

There are so many apps you can use to ensure such supervision, and it is important to keep all your gadgets and PC in a central area to ensure monitoring. This way, if the child is engaged for too long, you can check on him/her and set rules about usage of devices.

What is the most unforgettable child abuse case you have encountered?
Every case is heart-wrenching.

Children brought in dead as a result of abuse or neglect, young children physically and sexually abused are probably some of my unforgettable moments.

There will be some cases that stay in your mind for a long time. My youngest sexual abuse victim was only six months old.

Every child who has been abused deserves our attention and care. Preventing abuse is probably more important.

There is work to be done in this aspect. We might have made some advancements over the years, but we have room for improvement. We also need to improve the enforcement of all laws so we can provide a safer environment for all children.