Psychosocial dimension of hemophilia

It is important to understand the psychosocial dimension of hemophilia as psychological factors play a crucial role in the management of hemophilia.

Hemophilia is not only a disorder that affects an individual but something that upsets every other order in the family. The problem starts right at the point of diagnosis of hemophilia and breaking the bad news to the person and his family. There is a psychological trauma for the parents. The road to acceptance of hemophilia is marked by guilt, depression, anger and hence the importance of a caring and supportive community to help the families rise above hemophilia and lead normal lives.

Research has also found that psychological factors trigger bleeds. A correlation is found to exist between stressful life events and frequency of bleeding episodes. Similarly, anxiety and tension can also lead to bleeding. During the time of examination and festivals when there is heightened anxiety or excitement, children may have increased frequency of bleeding episodes, according to Vandana Janveja, Regional Psychologist, North

An attempt is made here to understand the common feelings experienced by a person with hemophilia as well the various members of his/her family. This understanding, could hopefully, help everyone understand each other and be compassionate to oneself and others.

General Feelings experienced by a person with hemophilia:

The following are some of the common feelings that a person with hemophilia could face:

- Feeling of Alienation & Low Self-esteem
- Guilt Feeling
- Displaced Anger
- Fear & Anxiety

Feeling of Alienation & Low Self-esteem

The person with hemophilia feels isolated from others of his age due to the inability to play with them or engage actively in all physical activities without fear or anxiety imposed by the disorder. He suffers from low self-esteem. He feels depressed. He thinks he is a burden to the family as all the family members try to readjust their routine to meet his needs. The high cost of treatment is crushing the family financially. He sometimes feels like committing suicide.
The following quotes from a few young persons with hemophilia will show how severely the disorder affects their psyche:

“I was branded as a haemophiliac with severe Factor VIII deficiency from infancy. I do not know why God is so cruel to me. Doesn’t He care for me? Is He punishing me for my sins in my previous life? Or, is it a punishment for the sins of my parents? Whatever the cause may be, the suffering—both physical and mental is weighing me down. I was a winning sprinter in UKG. Now I am a silent spectator to all my favourite sports and games. I have a bleeding in my right knee and left elbow very frequently.”

Although I am a 7th standard student I hardly go to school. Whenever I am at school, I am sick of the over-concern shown by teachers. They never allow me to play or run in the school. My friends know about my plight and they are afraid even to touch me. They treat me as if I am from another planet! Alienation is what I dread most.”

(From News Letter (December 1999) of Hemophilia Federation of India, New Delhi)

“I am at an age when I should be flitting in the sky like a butterfly. Yet even at this age, I have no confidence in myself, the reason being the disorder known as hemophilia which has been with me since I was born. Because of this disorder even ordinary injuries go on to become serious due to the deficiency of clotting factors in the blood. There are times when I hate myself. I prefer loneliness to the company of others. Sometimes I wonder why I alone am being subjected to this particular disorder. Because of frequent bleeds I have at times wanted to commit suicide. But I have refrained from taking that extreme step when I think of my family and their feelings. Because of hemophilia my education and career has become a question mark. I feel like a fish caught in the net.”

(From News Letter-March/2002)

Guilt Feeling

Sometimes a person with hemophilia takes on the burden of all family problems on himself, believing his condition of hemophilia is the root cause for everything. A feeling of guilt leads one on the road to self-rejection and can wreck a lot of harm on oneself. Hence it is very important that persons with hemophilia have a supporting environment that acknowledges and nourishes their innate gifts.

Displaced Anger

The frustration caused by the isolation from one’s peers and other discomforts, or difficulty in making adjustments, feeling rejected makes the person, in rare cases, takes his anger on his mother often blaming her for having placed him in such a predicament. Such pathological display of anger tends to aggravate the emotional stress of the mother who may be already smarting under guilt feelings. The person may also refuse to get treated regularly for the bleeds leading to avoidable complications.
Fear and Anxiety

Fear and feelings of anxiety are also common among people with hemophilia, esp. due to the unpredictable nature of spontaneous bleeds and the severe consequences that certain bleeds can cause. A constant underlying presence of such feelings could seriously hinder one from leading a normal life.

The fear of having to face all the difficulties associated with being identified as a person with hemophilia, sometimes unfortunately causes a person to not disclose that they have hemophilia. This is reflected in the following quotes:

“They are guys who try to bully you because they know you bleed easily”

“I can not go out for a movie or outing with them”

“I want friendship not sympathy from friends, especially girls”

“My sisters have problems finding a suitable match for marriage. people think of hemophilia as a disease, one that is contagious”

“I hate asking for privilege such as sitting at table because of a knee bleed when everybody else sits on the ground floor for a feast”

“Not every body (not all teachers) understands hemophilia and every year, it is the same story repeated”

“The girls will not even look at me let alone be friends, once they know I suffer from hemophilia”

Non disclosure has its own risk as will be seen from the following experiences:

“Once I had a serious injury while playing at school and though I knew I had hemophilia, I did not know anything else. I did not tell any one about the injury but when the bleeding did not stop I went to get first aid at the school clinic. When first aid did not seem to help they took me to a doctor and in the process of suturing the wound, it became a big mess. I had to be rushed to a major hospital and required a long stay there, all because my parents did not tell me the facts about hemophilia management.”
“A young man with hemophilia was never told about his status by his family. He got married and fathered two girls. One day he had a spontaneous head bleed but neither he nor his wife suspected anything and hence delayed informing anybody about it. He sought medical support quite late but since the doctor was not told about hemophilia, wrong treatment was given to him and sadly, the young man lost his life”

(Rema Menon, Regional Director, South in News Letter-March/2002)

As the person with hemophilia becomes older, problems like fear of rejection by others, problem in the work place, and problems with spouse may arise. Fear of condemnation, preparation for the possibility of dying, worries about leaving behind a family, guilt and anger are just some of the psycho social issues that need to be dealt with. It is therefore very important to have a supporting community that could help one work through these feelings and rise above them.

General feelings experienced among various members of a PWH’s family:

The condition of the person with hemophilia affects all the members of the family with anxiety and depression as it is a life long disorder with sudden emergencies involving expensive treatment.

Here below is a glimpse of the various kinds of problems that surface:

1. Between parents and child with hemophilia:

Parents feel guilty about having a child with hemophilia when seeing him suffer bleeds and pain. Some bleeds are spontaneous. However parents tend to feel that if they had been careful the child would not have had the bleeding. Some parents become angry or upset whenever the child gets a bruise or a bleed. The child reacts by not informing parents when there is a bleed.

There are parents who become overprotective and place many restrictions on the child’s every movement feeling it to be risky. The child thus either becomes more dependent on parents or defies them by indulging in risky activities to show that he is ‘normal’.

2. Feelings of Mother

Apart from the guilt feelings associated with the birth of a person with hemophilia, those who have a family history of hemophilia, suffer torture, in tradition-bound households, at the hands of husband, relatives and society. Having a son born with such an incurable disease is a stigma the mother has to live with.

Greater is the misery when she is abandoned by husband as she is tainted, incapable of bearing normal children. She may seek refuge in her parents who may or may not be in a position to help. However bringing up the child with hemophilia all alone, takes a heavy toll on her physical and mental health.
3. Between parents and other children (siblings)

By their pre-occupation with the child with hemophilia, parents tend to ignore other siblings in the family. They take out their feelings of frustration or anger over the bleeding episode of the affected child on other siblings. This may produce ill feelings among children in the same family. The nature of the disorder must be known to all members of family for better understanding and emotional support.

4. Feelings of siblings and daughters:

Living with a father/brother who is affected by hemophilia may make some woman take a mature and practical view of life. On the other hand such a situation may trigger a pessimistic attitude in some who may feel weighed down with more responsibilities since childhood of having to look after the person with hemophilia, sharing pain, frustration etc. She may think life unfair, unjust and may not be able to cope with negative experiences. Siblings may also tend to feel neglected thinking that too much attention is paid to the person with hemophilia. They may not like to make more sacrifices like giving up play or company of friends or TV in order to be with the affected person. When siblings reach marriageable age, they may feel that their prospect of getting married is threatened by the brother's or father's hemophilia. This may produce feelings of resentment or depression.

5. Between parents and neighbours or others

Fearing rejection or indifference parents choose not to apprise their neighbours or others about the child’s disorder. This aggravates their sense of isolation affects their normal social intercourse.

6. Between husband and wife

If husband has hemophilia he may hesitate at the start to tell his spouse about it. He may have fear that the spouse will not treat him the same way once she knows he has bleeding disorder. The fear may make him put off the decision to disclose interminably. The fact that he keeps his wife in the dark about the disorder will make him smart under feelings of guilt. If by accident the wife comes to know of the disorder during any injury or fall, the breach of trust may wreck the marriage keeping the spouse in the shock of having been betrayed. The bleeding disorder will have a long term impact on marriage relationship with knowing partner.

The partner also endures the many interruptions caused by the disorder, such as cancelled plans, irritable moods caused by severe pain, the aggravation of dealing with the fear that the partner is not recovering properly, or is getting worse. The partner may vacillate between trying to be supportive and understanding and lashing out in anger. Repetition of such episodes will tell upon the relationship adversely.

The disorder will affect the couple's sexual and reproductive life. The possibility of having a boy with hemophilia or a carrier girl needs to be accepted by both. Some may not choose to have any children while some may choose at the risk of having an affected one. Couples who
practise safer sex may have a feeling of missing out on a ‘normal’ sexual life. Partners can become frustrated with the unpredictability of bleeding which may lead to loneliness, isolation, depression, and disappointment. Some resolve these difficult feelings through open communication, but others may become angry and hardened or hide/suppress their feelings. When the disappointments are not addressed they get accumulated, causing the care-giving partner to feel burned out and withdraw or develop ‘compassion fatigue’ (running out of sympathy towards the chronically ill-partner). This progresses into resentment or indifference. The relationship becomes inflexible, painful and may not work any more.

It is possible for the chronically ill partner to under-function, while the other one to over-function. As the imbalance progresses, the over-functioner complains about having to do everything, but resists help. The under-functioner tries to assume some responsibilities but is pushed away by the over-functioner who believes that she can do it better or more quickly and more accurately. The relationship heads obviously towards a break-up.

**How does a couple overcome these problems?**

According to John M Gottman, PhD, the emeritus Professor of Psychology, University of Washington, the couple can balance the unavoidable problems of chronic illness with fun, romance, honest discussion of difficult feelings, and the determination to keep the illness in its place.