

Sharing a Hard Life: How Hemophilia Affects the Family

Chair: Ann Duffy, Ireland

Living with hemophilia can be a lonely journey, accompanied by feelings of anger, denial, shame, and frustration. The disorder adversely impacts the rest of the family as well. Panelists in this session recounted some of the hardships they've encountered in dealing with the disorder, as well as their strategies for managing the challenges.

Father's Perspective

Mohammed Aris Hashim, Hemophilia Society of Malaysia

Mohammed Aris Hashim described the economic and social burdens of hemophilia experienced by families, and particularly fathers, in developing countries. Often, little or no treatment is available in these countries; the disorder receives little health budget allocation and sometimes is not even recognized in the health system.

"Bleeding incidents are traumatic since it calls for the head of the family to make a tough decision. It's a choice of putting food on the table, buying bus tickets to the hospital, buying factor concentrates if the family can afford it, or buying cryoprecipitate, fresh frozen plasma, or blood," said the father of two adult sons with severe hemophilia.

A month's income can equal the cost of one single infusion, Hashim said. The need to earn more income often requires the father to work away from home, spending less time and bonding less with his children. Meanwhile, the mother copes alone with the daily stress of managing a child (or children) with hemophilia.

In most developing countries, hemophilia treatment consists of hospital-based on-demand therapy. Travel for treatment and prolonged hospitalization can put financial strain on the family. The World Federation of Hemophilia recognizes this hardship in its fact sheet on the economic benefits of home therapy, Hashim said. "In countries where home therapy is available, studies show a 400% reduction in clinic visits, and that eases the burden on public health facilities, as well as on the family."

Hemophilia can also bring social ramifications. Men with hemophilia may face marital, social, and professional limitations owing to mobility issues, repeated bleeding instances, or possibly a lower educational level resulting from missed school. Daughters who are hemophilia carriers may have difficulty finding a suitable marriage partner. "In a worst case scenario, a father may abandon his family to remarry and have healthy children—a sad situation for everyone in the family. If this happens, the welfare and well-being of his children, especially the hemophilic child, will worsen," he said.

Mother's Perspective

Haydee Benoit de Garcia, Fundacion Apoyo al Hemofilico (FAHEM), Dominican Republic

Haydee Benoit de Garcia described how her world changed when she learned about her son's hemophilia. With no known history of bleeding disorders in the family, her son's first bleed at six months of age was bewildering. She feared that her son would have no future, and her

husband, a professional baseball player, was devastated also, believing his son would be unable to play sports. “At this moment, I decided to take control of my family and to give my son the most normal life possible,” de Garcia said.

“The first years were a struggle, because every time he had a bleed we suffered. The next challenge came when it was time for him to begin school. My husband was worried he would be injured by the other children and wanted home-schooling, but I insisted he go to school and play with children his age,” she said. “I did not want to put my son in a bubble.” Adolescence came with difficult questions and constant conflict over which activities her son could engage in, and sometimes he hid his bleeds until he could not sustain the pain.

While her husband’s health insurance covered the cost of factor therapy, de Garcia said that most families in the Dominican Republic had no access to factor until two years ago. More than 75% of families with hemophilia are single mothers, because the father abandoned the family with the news of the child’s condition. The mothers must carry the burden alone without government support for the high cost of care.

As well as changing her life, said de Garcia, hemophilia has given her the opportunity to teach other families in similar situations how to cope with and overcome adversity. As president of the Dominican patient organization, she teaches families about the basics of hemophilia and ways to help their children live normal lives. She also lobbies the government to recognize hemophilia and provide treatment and care for this population.

Patient Perspective

Robert Lamberth, Australia

Robert Lamberth, who lives with the “troika of health complaints” – hemophilia, HIV, and hepatitis C, noted that while concern naturally focuses on the affected children, sometimes the plight of the rest of the family is overlooked. While parents worry about bleeding episodes, mobility issues, and ramifications on the child’s schooling and career, siblings may think they are missing out on their parents’ attention and so misbehave to gain attention, or may resent that the needs of the child with hemophilia always seem to come first.

Lamberth emphasized the need to provide continuing psychosocial support to the whole family as early as possible. “On the whole, living with an inherited bleeding disorder as part of the family does not need be that hard – or at least, it should be managed with appropriate care and support,” he said.

Open communication is essential to identify the needs of everyone in the family and develop ways to cope with stressful situations, anxieties, and fears. All family members need to understand their feelings and be able to express them in an environment of validation and support. Left unexpressed, emotions such as anger, fear, and guilt can grow and contribute to ongoing anxiety, shame, and low self-esteem, said Lamberth.

Appropriate education is also important, he said. For example, young women whose brothers have hemophilia need to be informed about the genetics of the disorder and the hereditary risks should they decide to have children. A well-resourced, family-focused hemophilia treatment

centre is key: “Dedicated bleeding disorders social workers and counsellors should be part of every centre, and we should be striving to achieve this in every healthcare delivery system,” he said.

Healthcare Provider Perspective

Elizabeth Fung, Children’s Memorial Hospital of Chicago, IL, United States

Elizabeth Fung, a clinical social worker, described some of the findings from her recent study on the impact of bleeding disorders on siblings. When compared with siblings in normal families, siblings in families affected by a bleeding disorder scored within the normal limits of psychosocial functioning. However, the study found that these siblings often feel deep longing for parental attention, guilt for being able to participate in activities that their sibling with a bleeding disorder cannot, and frustration when holidays or family events are disrupted by the disorder. The study also found these siblings to be highly attuned to such parental concerns as efficacy, infection, and treatment side effects.

Fung described some strategies for patients, parents, and hemophilia treatment centres (HTCs). HTCs help the family adjust to the diagnosis and locate financial resources and other support. They also guide patients and their families toward educational programs and networking opportunities, and can share the success stories of other patients, in language that fits with the family’s cultural and spiritual traditions, she said.

In the face of adversity, patients and family members require resilience. “What is right with you is more powerful than anything that is wrong with you,” said Fung. She advised parents to balance family needs and not make the bleeding disorder the entire focus of family life.

Support can help parents learn to cope with hemophilia-related stress and anxiety. In turn, parents can educate their children about the bleeding disorder, encourage them to express their feelings about the illness, and acknowledge those feelings. “A family is an interactive system, and any individual in the family can impact positively on the entire family system,” Fung said.