Hemophilia B Hurts Education, Job Prospects for Both Adult Patients and Caregivers, Study Finds

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Hemophilia B hurts educational and job prospects for both adults with the disease and caregivers of hemophiliac children, a recent study found.

The study, “Impact of mild to severe hemophilia on education and work by US men, women, and caregivers of children with hemophilia B: The Bridging Hemophilia B Experiences, Results and Opportunities into Solutions (B-HERO-S) study,” appeared in the European Journal of Haematology. It urges greater focus on career counselling and the importance of adequate insurance coverage.

Researchers at several U.S. hospitals and Danish healthcare giant Novo Nordisk recruited 299 adults with hemophilia B and 150 caregivers of children into the study, (NCT02568202).
The median age of the adult hemophiliacs was 29, while caregivers had a median age of 35. Most participants had completed four years of college, and among adults with hemophilia, 81 percent had part-time or full-time jobs; likewise, 86 percent of caregivers were also employed, as were 97 percent of their partners. Among those who were not employed, just over half had quit their jobs to take care of one or more children with hemophilia.

Yet 94 percent of patients said their hemophilia interfered with schooling — mainly because of bleeding episodes or pain that prevented them from attending classes or concentrating. Curiously, people with moderate hemophilia tended to have the most negative experiences, and were more likely than those with mild or severe disease to report having difficulty concentrating.

Among employed adults, 52 percent worked full-time (71 percent of women and 45 percent of men), while among the jobless, 62 percent had never worked; more than half said hemophilia and its complications kept them from working.

In addition, 95 percent of patients said hemophilia had a negative effect on job-related issues. As with education, those with moderate illness reported more negative impact than people with mild or severe hemophilia. People with more schooling were more likely to report hemophilia having an impact on their ability to work.

Among adults, 59 percent had received employment advice from a hemophilia healthcare professional. Patients with moderate hemophilia and those receiving preventive treatment were most likely to seek such advice.

Like adults with hemophilia, 89 percent of caregivers and 84 percent of their partners reported that caring for a hemophilia child hurt their ability to work. People caring for children with moderate disease or those in need of routine treatment were more likely to report a negative impact. People taking care of only one — as compared to two — hemophilia children, were also more likely to report a moderate to severe impact on work ability.
The study found that 31 percent of caregivers had left their job voluntarily to care for a child. Only 11 percent of caregivers, and 13 percent of partners, said caring for a hemophiliac child had no effect on their jobs.

“The results of the B-HERO-S study may be used beyond education to develop advocacy initiatives to ensure insurance coverage for adults with mild/moderate hemophilia B and affected women who need factor replacement to be able to continue to maintain employment in appropriate careers, and for children who need treatment to cover their daily activities, thus minimizing impact on their caregivers and siblings,” authors concluded.

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