

June 19, 2013

To Whom It May Concern:

My name is Jim Munn, R.N., B.S.N., M.S., and I am the program and nurse coordinator of the University of Michigan Hemophilia and Coagulation Disorders Program, as well as the chair of the World Federation of Hemophilia's Nursing Committee. I am writing on behalf of the Brazilian Federation of Hemophilia regarding the practice of home and self-infusion in persons with hemophilia. As you may know, hemophilia is a rare, X-linked condition in which one of the plasma proteins necessary for control of bleeding is absent or deficient (most often factors VIII or IX). At this time, the only way to replace the missing protein is through intravenous infusions of clotting factor concentrates. These infusions are given through a butterfly needle and are done by patients and family members in the home setting in almost every country of the world, certainly those with access to clotting factor concentrates for treatment. Since the incorporation of multidisciplinary, comprehensive care hemophilia treatment centers, patients and their families have been educated in home infusion with a number of positive outcomes and benefits realized – not only to the patient but healthcare as well.

As you might imagine, patients who do their own infusions at home have dramatically reduced times from onset of bleeding to receiving treatment, thereby decreasing both the number of infusions necessary to control bleeding and the amount of factor used, a substantial cost-savings over time. Additionally, earlier treatment leads to fewer complications related to bleeding, most notably joint arthropathy, which also will result in reduced disability-related costs. Cost, although quite important to the overall provision of health care, is not the only positive outcome of home and self-infusion. Patients and families will realize convenience, fewer missed days from work or school, less out-of-pocket expenses for travel to and from the hospital or treatment center to receive treatment (especially in patients living in remote areas or quite a distance from the treatment center), decreased waiting times and most importantly, a "normal" and higher quality of life. (1, 2)

A 10-year review conducted after the development of federally funded comprehensive care centers in the United States found the number of patients performing self-infusion had risen almost 5-fold with a number of other beneficial outcomes: less days lost from school or work (-73%), fewer unemployed adult patients (-74%), decreased number of hospital admissions (-89%), fewer days spent in hospital (-83%) and reduction in overall costs of care per patient per year calculated at 74%, not including the cost of factor concentrates. (3, 4)

Home and self-infusion requires coordinated education and training that is most often provided by treatment center nurses. Myriad approaches to teaching can be utilized when patients and families are taught to infuse factor concentrates. Many treatment centers have developed their own home infusion training materials and perform the teaching at the center. Other approaches to teaching home therapy have included family/patient infusion training weekends or retreats, camps that teach younger boys to self-infuse and teen retreats focusing on transition of care that emphasizes self-infusion.

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Numerous training materials have been developed to assist with teaching including infusion kits with artificial veins to practice on, rubber arms with veins that can be palpated and accessed by those learning infusions and even age-appropriate puppets with palpable veins and central venous access devices (CVADs) for those patients with poor venous access.

Oversight of such a program should be conducted by treatment center personnel, usually the nurse. Discussions with patients and families starting home infusions should be conducted regularly to ensure infusions are given as recommended and to ascertain if there are any concerns on the part of the patient, family or treatment center staff. Once implemented, home infusion can be very cost-effective and allow patients and families the ability to control their hemophilia instead of hemophilia controlling them.

I appreciate the opportunity to share the importance of home and self-infusion for patients with hemophilia and the positive outcomes that have been identified in the literature for those patients who use this approach to care. If you have any questions for me, please contact me.

Sincerely,

A handwritten signature in cursive script that reads "James E. Munn, R.N.".

Jim Munn, R.N., B.S.N., M.S.

Chair
World Federation of Hemophilia Nurses Committee

1. Berntorp E, Lethagen S. The role of home infusion therapy in haemophilia: a disease management perspective. *Dis Manage Health Outcomes*, 2000; 7(2): 77-81.
2. Santagastino E, Gringeri A, Mannucci PM. State of care for hemophilia in pediatric patients. *Pediatr Drugs*, 2002; 4(3): 149-157.
3. Aledort LM. Lessons from hemophilia. *N Engl J Med*, 1982; 306: 607-608.
4. Szucs TD, Öffner A, Schramm W. Socioeconomic impact of hemophilia care. *Haemophilia*, 1996; 2: 211-217.