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Supervised Self-Treatment

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At the 'van Creveldkhniek' Bilthoven, the Netherlands, an official home treatment (HT) program started in 1974. In this paper we will describe our personal experience with particular emphasis on problems in organization and the complications encountered.

In our clinic 278 patients are registered, 234 with haemophilia A, 40 with haemophilia B and 4 with severe von Willebrand's disease. The total number of patients with haemophilia in the Netherlands is estimated to be 1,150 (14.000,000 inhabitants). The clinic has basically two tasks. It is a primary care center (daily treatment of our own haemophilia patients, total number 92) and supervises care given elsewhere (an assessment is performed on 168 haemophiliacs from elsewhere once or twice yearly).

Since the official HT program started, 90 patients (32.7%) have entered this program. The entrance criteria are: (1) severe or moderate haemophilia A or B; (2) no circulating antibodies against factor VIII or IX; (3) frequent bleeding; (4) no occurrence of severe allergic reactions; (5) family and patients willing and able to follow the rules of the HT program.

The patients and families who are selected are carefully trained, theoretically as well as technically, after which they receive a qualification certificate. The theoretical training is considered the most important aspect.

In the age-class 0-15 years 16 of 65 patients (25%) are on HT; 15-30 years 56 of 152 patients (37%) and > 30 years 18 of 61 patients (29%). In the first group 2 patients under 4 years of age are succesfully treated by their parents. There are two types of treatment: prophylaxis (63 patients) and on-demand (27 patients). In case of haemophilia A, a higher consumption of replacement material in on-demand treatment at home is seen compared with on-demand treatment in the hospital (average annual consumption in units par patient on-demand in hospital: 33,000 U, on -demand at home 42,000 U). Prophylaxis demonstrated was no great difference (about 55,000 U Factor VIII/patient/annum). In about 90% of transfusions we make use of cryo-precipitate of both lyophilized and frozen products (small pools of 4 donors). Lyophilized products are manufactured by the Central Laboratory of the Red Cross Transfusion Service, Amsterdam. Frozen

Supervised Self-Treatment

41

products are obtained from several regional blood banks. Blood transfusion in the Netherlands is a self-supporting voluntary donor system.

All patients on HT are very positive about this form of treatment and none wishes to return to his old form of treatment. Nevertheless, the complications encountered were: Technical difficulties (3), hepatitis in parent (1), severe allergic reactions (shock) (1), occasionally mild reactions (35), and inappropriate treatment (3). Technical difficulties were few and not an important problem. However, hepatitis is a serious one as is severe allergic reaction. A number of patients report sporadic occurrence of mild allergic reactions (skin rash). If reactions occur more than sporadically we switch from cryoprecipitate to dried Factor VIII concentrates. This year the Central Red Cross Blood Laboratory started to produce dried factor VIII concentrates of intermediate purity for use within the Netherlands.

We investigated why only 30% of our patients are on HT. A large group of patients (15%) are reluctant to participate; also a number of physicians gave negative advice. In the Netherlands where distances are of little importance and intensity of care is high, HT may be not seem necessary by some physicians and patients. On the basis of 6 years experience with 90 patients in our home treatment program we may conclude that: (1) Even in a small country with short distances and high intensity of care HT is valuable. (2) In many cases replacement from demand therapy to prophylaxis should be considered. (3) Age is no contra-indication. (4) It is possible to organize a HT program with cryoprecipitate. (5) All patients put on HT stayed on it. (6) Success of HT program is highly dependent on the education given to patient and the family.

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